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Exploring the experience of stigma in severe mental illness – a Portuguese contribution to the validation of a psychometric instrument

Master Thesis in Mental Health Policy and Services

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ABSTRACT

We reviewed the evolution of concept of stigma, its correlates and consequences, and analysed psychometric instruments that were used to study personal experiences of stigma. We provided an insight over research of stigma in Portugal. We reviewed relevant studies that use Consumer Experiences of Stigma Questionnaire and documented psychometric properties of this instrument.

Our study aimed both to explore experiences of stigma in a Portuguese sample of people with severe mental illness and to contribute to the assessment of the psychometric properties of Consumer Experiences of Stigma Questionnaire and to the validation of its Portuguese translation.

We performed a cross sectional descriptive and analytic study, collected socio-demographic data and measured experiences of stigma and global functioning.

Frequency of responses regarding stigma section of CESQ matched previous studies using that scale. Frequency of responses in discrimination section was slightly lower than previously reported studies. We found an association between the discrimination score of CESQ and both male gender and living in the community. The discrimination score also positively correlated with global functioning.

Cronbach alphas for CESQ and its subscales were good. Intraclass correlation coefficients for CESQ and stigma subscale were also good. Using factor analysis we found most of the items in CESQ would fit 2 factors, grossly corresponding to the previously defined subscales.

We conclude that this study successfully explored stigma in Portugal, contributing in simultaneous to the validation of Consumer Experiences Questionnaire.

Keywords: Stigma, Experiences, Psychometric, Validation, Portuguese

RESUMO

Fizemos uma análise da evolução do conceito de estigma, das suas correlações e das suas consequências e analisámos os instrumentos psicométricos utilizados para estudar experiências pessoais de estigma. Revimos os principais estudos de investigação sobre estigma em Portugal. Revimos, igualmente, os estudos relevantes utilizando o "*Consumer Experiences of Stigma Questionnaire"* (CESQ) e as propriedades psicométricas já documentadas.

O nosso estudo teve como objetivos: explorar as experiências de estigma numa amostra portuguesa de pessoas com perturbação mental grave e contribuir para a documentação das propriedades psicométricas do *"Consumer Experiences of Stigma Questionnaire*" e para a validação da sua versão portuguesa.

Fizemos um estudo transversal, descritivo e analítico, recolhemos dados sociodemográficos e clínicos e medimos as experiências de estigma e o funcionamento global.

A frequência das respostas da secção de estigma foi semelhante à dos restantes estudos utilizando a CESQ. A frequência das respostas na secção de discriminação foi ligeiramente inferior à reportada noutros estudos. Verificámos a existência de uma associação entre a pontuação da subescala de discriminação, o sexo masculino e o facto de se viver na comunidade. A pontuação da subescala de discriminação está também correlacionada de forma positiva com o funcionamento global.

Os alfas de Cronbach para a CESQ e para as suas subescalas foram considerados bons. Os coeficientes de correlação intraclasse foram igualmente considerados igualmente bons.

Utilizando técnicas de análise fatorial, verificámos que a maior parte dos itens da CESQ se enquadrava em dois fatores, correspondendo sensivelmente às subescalas definidas previamente.

Concluímos que o presente estudo explorou com sucesso a questão do estigma em Portugal, contribuindo em simultâneo para a validação do *"Consumer Experiences of Stigma Questionnaire."*

RESUMEN

Hicimos un análisis de la evolución del concepto de estigma, de sus correlaciones y de sus consecuencias y analizamos los instrumentos psicométricos utilizados para estudiar las experiencias personales de estigma. Revisamos los principales estudios de investigación de estigma en Portugal.

Revisamos también los estudios relevantes utilizando "*Consumer Experiences of Stigma Questionnaire"* (CESQ) y sus propiedades psicométricas ya documentadas.

Los objectivos de nuestro estudio fueran explorar las experiencias de estigma en una muestra portuguesa de personas con perturbación mental grave y contribuir para la documentación de las propiedades psicométricas de "*Consumer Experiences of Stigma Questionnaire"* y para la validación de su versión portuguesa.

Hicimos un estudio transversal, descriptivo e analítico, cogemos datos sociodemográficos y clínicos y medimos las experiencias de estigma y el funcionamiento global.

La frecuencia de las respuestas en la sección de estigma fue parecida con la de los demás estudios utilizando la CESQ. La frecuencia de las respuestas en la sección de discriminación fue un poco más baja que en estudios anteriores. Verificamos la existencia de una asociación entre la puntuación de la sección de discriminación, género masculino y la vivencia en comunidad. La puntuación de la sección de discriminación esta correlacionada positivamente con el funcionamiento global.

Los alfas de Cronbach para la CESQ y para sus secciones fueran considerados buenos. Los coeficientes de correlación intraclases fueran considerados también buenos.

Utilizando técnicas de análisis factorial, verificamos que la mayoría de los itens de la CESQ se encuadraba en dos factores, que correspondían sensiblemente a las subscalas definidas previamente.

Concluimos que esto estudio ha demonstrado la cuestión del estigma en Portugal, y contribuyó de forma simultanea para la validación del "*Consumer Experiences of Stigma Questionnaire"*

"…All good people agree,

And all good people say,

All nice people, like Us, are We

And every one else is They:

But if you cross over the sea,

Instead of over the way,

You may end by (think of it!) looking on We

As only a sort of They!"

Rudyard Kipling, We and They, 1926

To Fátima and Gerardo for their legacy.

To Ana and to all my friends for the support.

To André for the future.

To all the righteous men and women who struggle daily to "cross over the sea" and to foster the society to «look on "We" as a sort of "They"»

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ACRONYMS

ARIA – Associação de Reabilitação e Integração da Ajuda

CASS - Clinician Assessment of Schizophrenic Syndromes

CAT - Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment

CESQ – Consumer Experiences of Stigma Questionnaire

CFA – Confirmatory Factor Analysis

CI – Confidence interval

CRPD - Convention on the Rights of People with Disabilities

DISC – Discrimination and Stigma Scale

DSM – Diagnostic and Statistic Manual of Mental Disorders

DSSS – Depression Self-stigma Scale

EDS – Experiences of Discrimination Scale

EFA – Exploratory Factor Analysis

FAPS – FAmilies of people with PSychotic disorders study

FBS - Frankfurter Befindlichkeits-Skala

GAF - Global Assessment of Functioning

GAS - Global Assessment Scale

HIV/AIDS – Human Immunodeficiency Virus / Acquired Immunodeficiency Syndrome

HSRS - Health Sickness Rating Scale

HSS – Stigmatisation Scale

ICCPR - International Covenant on Civil and Political Rights

ICD – International Classification of Diseases

ISE – The Inventory of Stigmatising Experiences

ISMI – Internalised Stigma of Mental Illness

KMO – Kaiser-Meyer Olkin statistic

M – Mean

MIDUS – MacArthur Foundation Midlife Development in the United States

MSA – Measures of sampling adequacy

MSS – Maristan Stigma Scale

NAMI - National Aliiance for Mentally Ill

PA – Parallel Analysis

PAF – Principal Axis Factoring

PANSS – Positive and Negative Syndrome Scale

PCM – Polychoric correlation matrix

PDD – Perceived devaluation and discrimination scale

PD-S - Paranoid-Depresivitäts-Skala

QOLI – Quality of Life Interview

RES – Rejection Experiences Scale

RMSEA - Root mean square error of approximation

SD – Standard deviation

SESQ – Self-esteem and Stigma Questionnaire

SFS – Social Functioning Scale

SLDS – Satisfaction with Life Domains Scale

SRER – Self Reported Experiences of Rejection

SS – Stigma Scale

SSMIS – Self-stigma of Mental Illness Scale

UDHR - Universal Declaration of Human Rights

WHO – World Health Organization

WLSMV - Means and Variance adjusted weighted least square

1 INTRODUCTION

1.1 ABOUT STIGMA

1.1.1 Why focus on stigma?

Stigma is defined as a sign of disgrace or discredit. Authors agree it is a powerful negative attribute, having its impact on all social relations.

Stigma is present everywhere in our society. It affects different characteristics in people, ranging from sexual orientation to HIV/AIDS, several medical disorders, gender, race, unemployment or obesity. However, in mental health disorders stigma has a devastating impact[1].

Discrimination, the enactment of stigma, appears closely associated to it. While stigma lies at the base of discrimination, discriminatory practices also promote and reinforce stigma. Discrimination is also about the conditions in which patients live, mental health budgets and the priority which we allow these services to achieve.[2] In other words, stigma and discrimination lead to social exclusion – a triad that is a key determinant in the mental health field.

Stigma and discrimination are violations of human rights. Intention and commitment to fight stigma are present in the spirit of legally binding treaties. Examples of those are the Universal Declaration of Human Rights (UDHR)[3] , International Covenant on Civil and Political Rights (ICCPR)[4], International Covenant on Economic, Social and Cultural Rights (ICESCR)[5] and Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (CAT)[6].
Fighting stigma and discrimination is explicitly mentioned on the Convention on the Rights of People with Disabilities (CRPD)[7] . CRPD actually demands that signatories 'take all appropriate measures to eliminate discrimination on the basis of disability by any person, organisation or private enterprise', and to 'adopt immediate, effective and appropriate measures … to combat stereotypes, prejudices and harmful practices relating to persons with disabilities … in all areas of life'.[7]
From the part of the World Health Organization, tackling stigma, discrimination and social exclusion is currently a major concern of the General Assembly, which reflects in the WHO Mental Health Action Plan 2013-2020[8].

At regional level, in the European Union, commitment to fighting stigma and discrimination is a consequence of signing treaties like European Convention on Human Rights, European Social Charter, European Convention on the Prevention of Torture and Inhuman or Degrading Treatment or Punishment. Recommendation Rec (2004)10, of the Committee of Ministers to

member states, is very specific about the protection of the human rights and dignity of persons with mental disorder.

Still at regional level, and in line with WHO Mental Health Action Plan, stigma and discrimination is one of the main action areas of European Mental Health Action Plan.[9]

At national level, fighting stigma, discrimination and social exclusion is a component of policies, plans and programs worldwide. For examples of anti-stigma programs, please see ASPEN Project country reports.[10]

In a time when quality mechanisms tend to be implemented into healthcare systems, there is also a trend to develop parts of quality standards that have statements on fighting stigma at a local level. NICE quality standards are a good example in the United Kingdom.[11] To implement stigma into quality standards is, by itself, a strategy to fight it, by turning each service user in a potential advocate, as Byrne noted[2].

Therefore, there is the need to foster the development of indicators that can be used regarding mental illness stigma.

1.1.2 Evolution of the concept

Stigma is a word that has its reminiscences in the Greek civilization. Stigma were body marks that were intentionally applied to individuals- the stigmatized - that carried unacceptable moral or individual traits, as compared to standards in that society. In Christian times, society has elaborated on the concept, adding two other meanings to those body marks – to indicate a holy grace or to indicate a sign of deformity/physical disease.[12] Anyway, those times, stigma implied, from the social point of view, firstly, "imputing a meaning into something" even if it did not have that meaning, and, secondly, dealing with deviations to a social norm.[12]

Goffmann[12] was the first author to theorize stigma. To Goffmann, stigma is the result of a gap between perceived attributes and stereotypes. It is a matter of perspective, not reality. it is "in the eye of the beholder". Stereotypes are selective perceptions that categorize people, and that exaggerate differences between groups ('them and us') in order to obscure differences within groups.[13]

He defines three types of attributes:

- Body(physical) – e.g. visible deformities in the body, deformity caused by physical disease
- Character (personal) – e.g. mental illness, criminal conviction
- Tribal (Social) – e.g. stigma of one group against another.

Goffmann also distinguishes between "discredited" and discreditable". Those concepts were further developed by Jones et al.[14] , who proposed six dimensions of stigma:

- Concealability indicates how evident or visible the characteristic is to other people.
- Course concerns over reversibility over time, regarding stigmatizing disorder. Irreversible conditions cause more negative attitudes than others.

- Disruptiveness indicates the extent to which a mark blocks or weakens interpersonal relations.
- Aesthetics reflects what is good-looking or attractive to one's perceptions. When applied to stigma, it means whether a mark provokes a reaction of aversion.
- Origin refers to how the condition began. Perceived responsibility on the conditions will carry more negative attitude.
- Peril, refers to feelings of threat induced in other people. This can mean physical threat (as in "contamination") or simply being uncomfortable.

According to Byrne, stigma is connoted with a few negative attributes. Shame is its first expression, resulting from perception as indulgence or as a weakness, despite centuries of knowledge, media campaigns and "the decade of the brain". Blame is also an attitude that appears associated to shame.[2] Maintaining secrecy is the maladaptive way some people find to cope with shame, but it can lead to deleterious consequences.

1.1.3 Development of stigma

According to Byrne, [2] negative attitudes towards people with mental illness exist since playschool and extend into early adulthood. This is suggested by several studies: Weiss[15] examined a cohort of children of elementary school age and confirmed the prejudices eight years after; Green[16] compared different studies, focusing public stigma, published within 22 years time. He found out that the results were remarkably consistent across all studies, which seemed to indicate that the community maintained consistent, long lasting negative attitudes towards the mentally ill. For Byrne,[2] this seems to object the common belief that with increased scientific knowledge about mental illness, stigma would tend to disappear.

1.1.4 Different concepts of stigma

The concept of stigma has evolved in the last fifteen years.

Link and Phelan have added discrimination to Jones' original dimensions.[17] Still, in 2001 the same authors present two major challenges for the concept of stigma.

The first challenge is that researchers who study stigma do so from their vantage point, privileging their own scientific theories and investigation methods rather than words and observations about people they study. This may lead to misunderstanding of the experience of people being stigmatized and to perpetuation of assumptions that are unsubstantiated.

The second challenge is about individualization of stigma and the fact that in research it tends to be considered as an attribute or a mark of the person rather than a designation or tag that others attach to an individual.

Thus, these authors propose a definition of stigma based on a convergence a few components:[17]

- Distinguishing and labelling human differences – oversimplification of salient differences between human beings occurs, with further labelling of individuals.

- Associating human differences to negative attributes – labels previously mentioned are associated to negative stereotypes, as previously described by Goffmann. Categories and stereotypes are often "automatic" and facilitate "cognitive efficiency". For the authors, from a psychological standpoint, culturally given categories are present even at a preconscious level and provide people with a means of making shorthand decisions that free them to attend to other matters.
- Separating "us from them" – Social labels connote a separation between the group that stigmatizes ("us") and the group that is being stigmatized ("them"). For example, some people talk about people who have schizophrenia as being "schizophrenics".
- Status loss and discrimination – stigma leads to loss of status in social hierarchy, and to discrimination, both at individual and at structural levels.

Link and Phelan also emphasize that stigma is a matter of power – certain groups in the society have the power to stigmatize. Stigma is also a matter of degree – there is a continuum between its existence and its absence.

Corrigan[1] focused on cognitive and behaviour features of mental illness. He proposed a model in which stigma was categorized either as public or self-stigma.

Public stigma is defined as the reaction that the general population has to people with mental illness. Self-stigma is the prejudice which people with mental illness turn against themselves.

In each of the categories, stigma is broken down into three elements: stereotypes (cognitive knowledge structures) prejudice (cognitive and emotional consequence of stereotypes) and discrimination (behavioural consequence of prejudice)[18] .

Thornicroft et al.[19], elaborate on this framework, stating that stigma is composed of problems at three levels: knowledge, attitudes and behaviour.

Mental health knowledge is also known in the literature as mental health literacy. Research by Jorm et al. in Australia has shown that better mental health literacy was correlated with better recognition of the features of mental illness, and potential better compliance with help seeking or medication and/or psychotherapy compliance.[20] Nevertheless, according to Thornicroft[19], despite improvement in mental health literacy, a series of government surveys in England between 1993 and 2003 revealed a mixed results regarding its impact on attitudes towards people with mental illness. Therefore, this author concludes that "an increase in knowledge about mental illness does not necessarily improve either attitudes or behaviour towards people with mental illness."

Negative attitudes, also known as prejudice, is the most studied component. According to Thornicroft, it can predict more strongly actual discrimination than do stereotypes. Attitudes have been widely researched. There are studies regarding both public, healthcare practitioners (and medical students) and caregivers.

Thornicroft emphasizes the importance of studying actual behaviour, stressing that most of the studies have focused on attitudes towards hypothetical situations, rather than on actual

stigmatizing and discriminative behaviour. He therefore proposes a shift from research focused on stigma to research focused on discrimination.[19]

1.1.5 Correlates and consequences of stigma

Stigma can have profound impact both at individuals with mental illness and their relatives.

Rüsch et al.[18] list four negative consequences of public stigma:

- Everyday life discriminations encountered in interpersonal relations and depictions in media
- Structural discrimination – inequity in the access to opportunities in private and public institutions.
- Self-stigma (versus empowerment)
- Fear of stigma as a barrier to use health services.

About self-stigma and empowerment, Rüsch et al. comment, firstly, that self-stigma and empowerment are on the same continuum of self-esteem. They also remark that people may have different reactions to public stigma – while some people react with low self-esteem (being self-stigmatized), others might react with anger or indifference. They point out that a possible explanation for this resides both within group identification with public stigma and perceived legitimacy of it. They also point the issue of self-disclosure – a person who considers mental illness is a part of his/her identity will more likely reveal his/her condition to others.

Secondly, they comment on the relationship between stigma and service use. People decrease usage of psychiatric services in order to overcome public stigma. This is supported by evidence showing associations of this lack of usage with negative reactions from family members and poorer social status.

Lack of usage of psychiatric services is intrinsically linked to decreased treatment compliance and, therefore, poorer prognosis.[21,22]

In a systematic review and meta-analysis conducted by Livingston and Boyd, internalized stigma has shown to be associated with variables at different domains.[23]

In the psychosocial domain, stigma has been negatively associated with hope, self-esteem, empowerment/mastery, self-efficacy, quality of life and social support/integration, both at group and individual levels.[23–25]

In the psychiatric domain, stigma has been positively associated with symptom severity and negatively with treatment adherence[23]. Still according to Livingston and Boyd, there are mixed results regarding association of stigma to diagnosis, illness duration, treatment setting and functioning:

- Regarding diagnosis, only 10 of the 25 studies in Livingston and Boyd's systematic review seemed to show a significant relationship between schizophrenia spectrum and stigma. From those, 3 have shown a positive association and 1 has shown a negative association.[23]

- Concerning illness duration, in the same review, from 14 studies found, 5 have shown a significant relationship. 4 of them seem to have found a negative association. 1 documents a positive relationship.[23]

- Regarding treatment setting, from 10 studies reviewed by the previews authors, only 3 have found a significant relationship between hospital setting and stigma. From those, two showed a positive relationship.[23]

- Still in the same systematic review, concerning functioning, from the eight studies, four of them have shown a negative relationship with internalized stigma[23]. We should also note Lundberg et al. found associations between more frequent rejection experiences and a lower degree of global functioning.[26]

- Regarding setting of treatment, Angermeyer et al. [27] found that patients in old state psychiatric hospitals had less perceived and anticipated discrimination than patients living in the community. Chee et al. [28] found perceived stigma to be higher patients with schizophrenia living in the community but the opposite when patients had other diagnosis.

- Regarding socio-demographic variables: from the 35 studies found by Livingston and Boyd, only 11 seemed to show a significant relationship between age and internalized stigma. From those, 4 have shown a positive relationship and 7 a negative relationship. From 38 studies comparing gender, male gender seemed to be significantly associated with stigma in 4 of the studies. In 3 of them female gender seemed to associate with more stigma. Employment status was studied in 14 articles. 4 of them seemed to show a significant association with being unemployed. Regarding marital status, only 1 of 11 studies found seemed to show a significant association between being married and suffering more stigma. Another seemed to document a negative association between those variables.[23]

1.2 STIGMA RESEARCH

Wahl, in 1999, mentions four types of stigma research:

- Research that involves self-reports from general public.

- Research using vignettes or profiles of individuals and study participants' ratings of people described.

- Analogue behaviour studies, ("experimental studies") in which people are led to believe they are dealing with a person with mental illness.

- Research focused on mental health consumer, and his personal experiences of mental stigma.

The latter type of research, according to Wahl, was, at the time, scarce. [29]

The paradigm seemed to have gradually changed in the last decade and nowadays there is a relatively large number of instruments to measure personal experiences of mental stigma.

1.2.1 Instruments to measure stigma - categories and criteria for psychometric properties

In 2010, Brohan et al. [30], reviewed systematically 75 studies with instruments to measure personal experiences of mental stigma. The authors considered instruments to measure personal experiences of stigma in three categories:

- Perceived stigma
- Self-Stigma
- Experience of stigma

They describe the instruments and group them, according to those categories. They also reviewed those instruments, regarding quality criteria for health status questionnaires presented by Terwee et al.[31] Those criteria are briefly described in Table 1.

Table 1 - Criteria for quality of psychometric instruments (adapted from Brohan et al. and Terwee et al.) [30,31]

Content validity	Clear description is provided of the measurement aim, target population, concepts that the questionnaire is intended to measure, and investigators or experts involved in item selection
Internal consistency	Factor analysis performed on adequate sample size (minimum of 100 subjects, 4 to 10 subjects per variable); Cronbach alpha between 0.70 and 0.95
Construct validity	Specific hypotheses should be assessed (e.g. expected correlations between measures or expected differences in scores between “known” groups); at least 75% of the results are in correspondence with those hypotheses in a subgroup of at least 50 patients
Test-retest reliability	Intraclass correlation coefficients (ICC) or cohen’s Kappa ≥ 0.70 in a sample of at least 50 patients
Floor-ceiling effects	Are considered to be absent if less than 15% of respondents achieved the lowest or the highest possible score.

Brohan et al. found fourteen measures, used in the studies, which are listed in

Table 2, and that were, thus, grouped in each of those categories. To these measures, we should add Maristan stigma scale (MSS).

Table 2 - Scales assessing stigma experienced by people with mental illness (Adapted from Brohan et al.[30])

Scale	Measures Perceived stigma	Measures experience of stigma	Measures self-stigma	Measures other
PDD – Perceived devaluation and discrimination scale[32]	Perceived discrimination (6 items) Perceived devaluation (6 items)	No	No	No
ISMI – Internalised Stigma of Mental Illness[33]	No	Discrimination experience (5 items)	Alienation (6 items) Stereotype endorsement (7 items) Social withdrawal (6 items)	Stigma resistance (5 items)
SSMIS – Self-stigma of Mental Illness Scale[34]	Stereotype awareness (10 items)	No	Stereotype agreement (10 items) Stereotype selfconcurrence (10 items) Self-esteem decrement (10 items)	No
CESQ – Consumer Experiences of Stigma Questionnaire[29,35]	No	Experiences of stigma (9 items) Experiences of discrimination (12 items)	No	No
RES – Rejection Experiences Scale[36]	No	Rejection experiences (11 items)	No	No
DSSS – Depression Self-stigma Scale[37]	Public stigma (4 items)	Stigmatizing experiences (6 items)	General selfstigma (9 items) Secrecy (9 items)	Treatment stigma (4 items)
SRER – Self Reported Experiences of Rejection[38]	No	Rejection experiences (12 items)	No	No
SS – Stigma Scale[39]	No	Discrimination (12 items)	Disclosure (11 items)	Positive aspects (5 items
ISE – The Inventory of Stigmatising Experiences[40]	Perceived stigma 2 items	Experienced stigma 2 items	Social withdrawal 1 item	Impact of stigma (5 item)

SESQ – Self-esteem and Stigma Questionnaire[41]	Feelings of stigmatisation (8 items)	No	No	Self-esteem (6 items)
HSS – Stigmatisation Scale[42,43]	Perceived stigma (15 items)	No	No	No
MIDUS – MacArthur Foundation Midlife Development in the United States[44]	No	Major discrimination (11 items) Day to day discrimination (11 items)	No	No
DISC – Discrimination and Stigma Scale[45,46]	Anticipated discrimination (4-items)	Experienced discrimination (32 items)	No	No
EDS – Experiences of Discrimination Scale[47]	No	Has discrimination occurred (1 item) Specific settings of discrimination (8 items)	No	Stressfulness of discrimination in specific settings (8 items)
Maristan stigma scale (MSS)[48]	Health professionals (4 items)	No	Self-Stigma (4-items)	Informal Networks (11 items) Socio-institutional (12 items)

1.2.2 Perceived stigma

Perceived or felt stigma, according to Scambler et al[49] original definition, refers principally to the fear of enacted stigma, but also encompasses a feeling of shame associated with the illness. Van Brakel et al[50], however, remove the feeling of shame from that definition, considering research about perceived stigma as research in which "people with a (potentially) stigmatized health condition are interviewed about stigma and discrimination they fear or perceive to be present in the community or society".

Perceived stigma can refer both to what an individual thinks most people would believe towards a certain group of the society or what that individual thinks about him personally as a member of a stigmatized group.[51] Components of perceived stigma reported in the literature as measurable variables include stereotype awareness (perception by the individual of how individuals with mental illness are viewed by "most other people" in the society)[1] and personal expectations or fears of encountering stigma.

Perceived stigma is addressed in the vast majority (79%) of the studies reported by Brohan et al. Seven measures were used in the literature to measure it: Perceived devaluation and discrimination scale (PDD)[32], Self-stigma of Mental Illness Scale(SSMIS),[34] The Inventory of Stigmatising Experiences (ISE) [40], Stigmatization Scale (HSS)[42,43], Self-esteem and Stigma Questionnaire(SESQ) [41],

Depression Self-stigma Scale(DSSS) [37] and Discrimination and Stigma Scale(DISC)[45,46]. To those measures, we should add Maristan Stigma Scale (MSS).[48]

PDD[30,32] is the most commonly used scale. It totals 12 items - its two subscales measure perceived discrimination and perceived devaluation – a way of measuring stereotype awareness. Perceived stigma is also measured in 10 item stereotype awareness subscale in SSMIS[34]. HSS investigates perceptions of how the person feels they have been personally viewed or treated by the society. In 2 of its items, DISC addresses the expectation of being stigmatized in various aspects of life – a concept called anticipated discrimination. MSS[48,52] "health professionals" subscale measures patients' perceived stigma regarding interactions with healthcare professionals. Therefore, in our opinion, although measuring interaction in a specific setting, it would fit in perceived stigma category.

Regarding psychometric properties, all of the measures above mentioned have reports on content validity. On PDD, SESQ and DSS, it is not known if the target population was involved in selecting items in the scale. DSSS and SESQ meet aforementioned criteria of internal consistency. PDD, SSMIS, ISE and HSS, do not have reports of factor analysis, although Cronbach's alphas meet defined criterion level. SSMIS and SESQ have studies in which test-retest reliability is measured. MSS has been multiculturally tested, and its content validity was assessed. Cronbach alpha, internal consistency and test-retest reliability have been reported and meet criteria defined by Terwee et al.

1.2.3 Self-Stigma

As mentioned, self-stigma is considered the internalization of the public stigma.[34] For Corrigan et al, there are three components in self-stigma:

- Cognitive response - negative belief about the self (e.g., character weakness, incompetence)
- Affective response - agreement with beliefs expressed by the public or the society and negative emotional reaction (e.g., low self-esteem, low self-efficacy)
- Behaviour response to prejudice (e.g., failing to pursue work and housing opportunities)[1,53]

Self-stigma is assessed by Internalised Stigma of Mental Illness(ISMI)[33], Self-stigma of Mental Illness Scale (SSMIS)[34], Depression Self-stigma Scale[37] (DSSS), Stigma Scale[39] (SS) and The Inventory of Stigmatising Experiences[40](ISE).

Alienation, stereotype endorsement and social withdrawal subscales in ISMI measure self-stigma, which correspond to its affective, cognitive and behavioural dimensions[54]. SSMIS measures self-stigma through three sub-scales: stereotype agreement; stereotype self-concurrence and self-esteem decrement[30,34]. SS has a "disclosure" subscale, which focus on the three dimensions already mentioned[30,39]. ISE contains one item on social withdrawal[40]. DSSS addresses self-stigma through two subscales – general self-stigma and secrecy: general self-stigma measures personal stereotype awareness. The secrecy subscale is comparable to the

social withdrawal subscale in ISMI and disclosure scale in SS[37]. MSS[48,52] has a 4 item subscale on self-stigma.

According to Brohan, all the measures have reports on content validity. DSSS does not have disclosed data about target population and involvement in item selection. SSMIS and ISE's Cronbach's alpha values meet criteria by Terwee et al. but factor analysis is not reported. ISMI; DSSS and SS have both factor analysis and acceptable Cronbach alphas.

ISMI, SSMIS and SS have their test-retest reliability measured, and meeting aforementioned criteria.

1.2.4 Experience of stigma

According to Brohan and van Brakel, experience of stigma is the "experience of actual discrimination and/or participation restrictions on the part of the person affected"[30,50].

For the purpose of this definition, measuring experience of stigma can refer to measuring experiencing stigma in general or a report of experiences of stigma in specific situations or areas of life.[30]

By measuring experience of stigma, one can, thus, assess direct effects of public stigma on the stigmatized individual.

Measures of experience of stigma include ISMI, CESQ, SRES, DSSS, SRE, SS, ISE, MIDUS, DISC and EDS.

CESQ will be addressed in a separate chapter. We should note it is the most used scale that addresses only experience of stigma.[30]

ISMI's discrimination experience subscale has 5 items. It addresses both perceived discrimination and general experiences of discrimination.[54]

RES also measures self-stigma through both its subscales. However, it is developed only in Swedish.

SS discrimination subscale has 12 items on general stigma experiences and specific experiences.[39] ISE has two questions on general stigma experiences.[40] DSSS contains 6 items about feelings of stigmatization after experiencing or disclosing depression.[37]

DISC has 32 items addressing personal experiences of stigma in several areas of life.[45]

MIDUS[44] and EDS[47] examine, besides experience of stigma, reasons for stigma.

From the psychometric point of view, we should note that RSE, DSSS, SRE and EDS do not have studies that clarify target population involvement in selecting the items; EDS does not have reports on internal consistency. ISMI, DSSS, SS and MIDUS meet full criteria for internal consistency, according to Terwee et al.. DISC[46] RES, SRE and IDE have been reported to have Cronbach's alpha calculated with acceptable values, but have no factor analysis; only SS and ISMI measure test-retest reliability with acceptable values.

Other subscales identified in Brohan's review measure additional elements of stigma, not covered by the perceived, experienced and self-stigma categories. Those include ISMI's "stigma resistance", SS's "positive aspects", "self-esteem" in SESQ, "treatment stigma" in DSSS and "stressfulness of stigma events" in EDS.

Stigma resistance, positive aspects and self-esteem seem to be, according to Brohan et al, more related to self-estigma. Treatment stigma does not measure mental health stigma, but a related construct. "Stressfulness" is more related to discrimination, as it measures magnitude of experienced discrimination.

MSS's informal networks subscale measures stigma perceived and experienced by the individual on the part of their informal network of care. It would be related with perceived and experience of stigma. Socio-institutional subscale measures aspects related to perception about mental health services organization.

CESQ psychometric properties will be summarized in Section 1.3.2.

1.2.5 Stigma studies in Portugal

In Portugal, there have been few studies about stigma in mental illness.

Most of the studies published so far are on the public stigma.

In 2008 Loureiro et al. conducted a study about population's attitudes and beliefs towards patients with mental illness in 834 individuals in the general population. They found out that public tolerability regarding people with mental illness is high. However, more authoritarian attitudes are related to beliefs in dangerousness and incurability.[55]

Later, authors from the same working group translated and adapted a Portuguese version of the Survey of Mental Health Literacy in Young People, by Jorm et al. (QuALISMental)[56]

In 2013 Loureiro, Jorm et al. conducted another study in which they assessed mental health literacy about depression in adolescents and young people. They applied the QuALISMental to 4938 Portuguese young people between 14 and 24 years. They found out several deficits in the mental health literacy of respondents – failure to recognize depression on a vignette, and lack of knowledge about helpful treatments[57]

Palha and colleagues in the NGO "Encontrar-se"[58] have been active in this field of research and advocacy. In one of their studies they evaluated perceptions regarding people with mental illness in a sample of 285 university students. Students perceived people with schizophrenia as unpredictable, hard to talk, feeling different than the others and not improving without treatment. On the other hand, people with substance abuse were perceived as dangerous.[59]

There is also work from Campos et al. evaluating an intervention to improve knowledge about mental illness in adolescents, with ages ranging from 15 to 18 years old. Quoting their results, "post intervention assessment showed a significant increase in the total score of the perceptions of knowledge; no significant differences in stigmatizing perceptions; and a significant decrease in help-seeking intentions when facing a mental health problem, although most participants have come to consider different types of help".[60]

More recently, Campos et al. evaluated knowledge about mental illness in younger adolescents, aged 12 to 14 years old before and after an intervention. Results showed a reduction in stereotypes and increase in knowledge about mental illness, as well as better recognition of mental health conditions and improved help-seeking behaviour, with the intervention.[61]

Chambers, Botelho et al. applied the Community Attitudes towards the Mentally Ill (CAMI) scale to 810 nurses working in psychiatric wards and units and community facilities in a multicentre study with participations from Finland, Lithuania, Ireland, Italy and Portugal. One hundred and twenty four of them were from Portugal. They found that Portuguese nurses had more positive attitudes towards mentally ill than nurses from the other countries studied. Positive attitudes are associated with being female and having a senior position.[62]

There is also work from Gonçalves Pereira et al., regarding stigma in 108 caregivers. They used the stigma subscale of the Szmukler et al's Experience of Caregiving Inventory as part of comprehensive assessments to explore the consequences of caregiving. Sense of stigma was one of the covariates for the negative impact of caregiving in a regression model.[63]

Personal stigma has been increasingly studied over the last few years.

There is record of an authorized translation of ISMI[64], but, to best of our knowledge, there are no psychometric studies about it.

The Maristán stigma scale, previously mentioned in section 1.2.1, has been translated to Portuguese. It was validated in using a sample collected in several countries including Portugal. Items of the scale were developed through focus groups. Factor analysis was made and test-retest reliability was assessed. The Portuguese subsample was composed of 20 patients with schizophrenia or a related psychosis (out of 164 on the global sample). [48]

We should also note a study by Sousa et al.[65] In that study, which aimed to study relationship between self-stigma and recovery potential, the authors applied a Portuguese authorized translation of ISMI, as well as the Recovery Assessment Scale, to 50 outpatients with schizophrenia. They found that participants had moderate scores in discrimination experiences subscale of ISMI. They also found a moderate negative correlation between the stereotype endorsement subscale of ISMI and recovery potential in schizophrenia.

To the best of our knowledge, there are no published Portuguese studies specifically on what has been defined, strictly speaking, as the experience of stigma.

CESQ, the most studied scale that measures experience of stigma,[66] has an authorized European Portuguese translation, but its psychometric properties had not been documented until now.

1.3 CONSUMER EXPERIENCES OF STIGMA QUESTIONNAIRE (CESQ)

The CESQ was developed in 1999 by Wahl [29], with the collaboration of the National Alliance for Mentally Ill (NAMI).

Its development was based on the fact that most of the research on stigma until then seldom focused on the real life experience of mental health consumer.

The questionnaire is available as a self-reporting tool, but has also been administered in face to face interviews.[35]

Dickerson et al. modified the questionnaire by replacing the term "consumer" in the text by "person who has mental illness", person who has a psychiatric disorder" or "person who uses psychiatric services".[35] Sample items from versions developed by Wahl and by Dickerson et al. are available, respectively, in Annexes 2 and 3.

The questionnaire has two sections. The "stigma" section and the discrimination section include, respectively, nine and twelve items.[29,35]

It was translated into Chinese[67], and Polish[68–70]. Psychometric data were not reported for Chinese translation.

There is also a Portuguese authorized translation of CESQ, with its corresponding backtranslation[71] , which remained unpublished until now.

1.3.1 Research involving CESQ

In Wahl's original study, a postal survey which had 1301 respondents, obtained from the NAMI mailing list. Respondents had been diagnosed mainly with bipolar disorder (25%) but also with schizophrenia (19%) and major depression (15%).

Most commonly reported stigma experiences included witnessing stigmatizing comments about mental illness (50% often or very often), encountering hurtful or offensive media portrayals of it (47% often or very often), or being treated as less competent by others once their illness had been disclosed (36% often or very often). Twenty six percent of the respondents often had the experience of sometimes being shunned or avoided. Sixteen percent reported seldom or never receiving support from friends. More than half (55%) of them said they worried that others would view them as service users.

Discrimination experiences, such as being turned down for a job, were less reported: one in three respondents reported that they had been turned down a job, and 28% found work environment unfriendly.

Wahl's study has a few limitations. First, it is based in a sample of patients affiliated with an advocacy organization, and who chose to respond to a stigma questionnaire. Wahl himself questions if it represents the typical mental health service user. Secondly, it is based in a heterogeneous sample, which includes both patients with severe mental illness and patients with common mental illness. Thirdly, it does not establish a correlation between stigma and other variables such as patients socio-demographic characteristics, illness severity, gender, mood-related variables, or illness insight[29,35].

Dickerson et al.[35], in 2002, applied the CESQ to 74 outpatients with schizophrenia. They administered CESQ in face-to-face interview. They assessed symptom severity, quality of life and social functioning, socioeconomic status, gender, mental illness attribution and depression.

Item to scale correlations were calculated, regarding stigma and discrimination section of CESQ. All of the items in the stigma section correlated within acceptable limits with total score for that section. Only 6 of 12 items in the discrimination section correlated within acceptable limits with total score for discrimination.

In their sample, Dickerson et al. found that the ranking of responses was similar to the one that had been found with the NAMI-affiliated sample studied by Wahl. However, average ratings of CESQ items were higher in Wahl's sample, meaning patients affiliated with NAMI would more frequently report stigma experiences.

Surprisingly, they did not find correlations between stigma and psychiatric symptoms, depression, subjective satisfaction with living situation or subjective satisfaction with safety.

There was an inverse moderate correlation between several subjective variables from the quality of life scale and the stigma total score: subjective satisfaction with daily activities, subjective satisfaction with family contact, subjective satisfaction with finances, and subjective satisfaction with health. The variable measuring "Perceived Adequacy of Finances to Meet Daily Needs" from the Quality of Life Interview was moderately and inversely correlated with total stigma score. In a multiple regression analysis model on the stigma total score, where the former variables were entered, only the perceived adequacy of finances remain significant in the equation.

Socioeconomic status based on parental occupation was moderately correlated with discrimination total, and remained significant in univariate comparisons.

Bagley and King did an exploratory analysis on three stigma scales, including CESQ. They analysed 13 of the items for scalability. Criteria for scalability of the item were: correlation of 0,4 or greater with the scale total and the resulting scale having an alpha value of at least 0,80.[42] They found that only 7 of the 13 items did fulfil criteria for scalability. The study does not address the fact that there are two subscales in CESQ, and authors do not calculate alpha value for both subscales nor does a factor analysis.

Switaj et al.[68], in 2009, applied stigma section of CESQ to 153 inpatient and outpatient patients with schizophrenia, diagnosed according to ICD-10 criteria, aged between 18 and 65 and that were not dependent on drugs of alcohol. They also applied Satisfaction with life domains (SLDS) scale in order to assess subjective quality of life, Global Assessment of Functioning (GAF) for global functioning, Frankfurter Befindlichkeits-Skala (FBS) and Paranoid-Depresivitäts-Skala (PD-S) to assess patient rated severity of symptoms and Clinician Assessment of Schizophrenic Syndromes (CASS) in order to measure severity of psychiatric symptoms.

Regarding CESQ, they found out that up to eighty-six percent of the patients avoided to disclose the fact that they are receiving psychiatric treatment to people outside the family. Forty to seventy percent of the patients reported, at least sometimes, the following experiences: being avoided by others, treated as less competent, advised to lower one's expectations in life, having worried about being viewed unfavourably by others, hearing negative comments about the mentally ill or encountering offensive media depictions of mental illness. The questionnaire has shown good internal consistency. (Cronbach's alpha = 0.79)

Regarding relationships between clinical and social-demographic characteristics and stigma, they found a negative association with subjective quality of life, which matches previously described data.

They also found, through stepwise regression multiple analysis of socio-demographic and clinical characteristics and stigma that patients who became ill at a younger age felt more stigmatized.

There was a positive correlation between stigma and patient rated symptoms, in both Paranoid and Depressive subscales of PD-S.

They found no significant associations, between the level of stigmatization experienced by the participants and age, sex, education, marital status, housing status, current employment or number of years in employment, type of psychiatric setting, duration of illness, number of involuntary hospitalizations, medication side effects, social functioning and overall severity of clinician rating symptoms. This is consistent with results reported by Dickerson et al.

In a new study (2012), Switaj and colleagues[69] also applied CESQ to 442 patients, treated in various psychiatric care facilities in Warsaw. 63% of them were diagnosed with psychotic disorders, and 14% of them with affective disorders. In accordance with the previous study, a majority of patients reported having often or very often avoided telling others about their mental health problems. More than a third indicated having often or very often heard others make unfavourable or offensive statements about people with mental illness, worried about being viewed unfavourably by others, and been treated as less competent. Nevertheless, it should be noted that only a small fraction of subjects believed that people who knew about their illness seldom or never treated them fairly, and that their friends were not understanding and supporting.

Regarding discrimination experiences, they were less reported, in parallel with what happened in previous studies[29,35] : Just above half of those interviewed said that in their written applications for jobs, housing, school, or licenses of all types they often or very often avoided mentioning that they are in psychiatric treatment. Approximately 1 in 4 respondents said that their colleagues or superiors at work who knew about their mental health problems seldom or never were supportive and accommodating, and about 1 in 5 thought that representatives of the justice system had not treated them with consideration and kindness. Slightly less than 10% reported that they were often or very often turned down for a job.

In 2013, the same group conducted a secondary analysis of the previous described samples, performing a factor analysis in order to assess construct validity of stigma section of the scale[70].

They decided not to use the discrimination section of CESQ. This decision is due to the fact that in their sample, the discrimination section was proved to have unsatisfactory internal consistency (Cronbach's $\alpha = 0,63$), which is corroborated by work by Solomon et al[72] and to the fact that as many as 7 items in the discrimination section were only endorsed by a marginal proportion of respondents.

They selected only cases which completed the full stigma section –373 in their 2012 study (sample one) and 136 sample of the 2009 study (sample two).

Regarding data analysis, they started to randomly split sample one in two demographically and clinically equivalent subsamples.

Internal consistency of the 9-item stigma subscale was not acceptable regarding inter-item correlation (0,302 in sample one and 0,282 on sample two), although Cronbach alpha has acceptable in both samples. (0,799 and 0,788 respectively).

Two of the items in the Stigma subscale were found to be psychometrically poor in exploratory factor analysis and were, thus, discarded. The remaining 7 items model parameters of fit were in the acceptable ranges in confirmatory factor analysis.

Concurrent validity was assessed using SLDS (quality of life), PD-S, FBS (patient reported symptoms), GAF (global functioning) and CASS (clinician-rated symptoms). Pearson correlations of the 9 item scale and 7-item scale both seemed to show moderate correlations with satisfaction with life domains and patient reported symptoms, but not with global functioning or clinician rated symptoms.

Lv et al.[73] applied CESQ to measure discrimination and ISMI, to measure self-stigma. They found the most scored items were “Have you avoided telling others outside your immediate family that you have received psychiatric treatment” and “Were your friends understanding and supportive when they learned you have received psychiatric treatment?” They have found that self-stigma in all its domains (alienation, sterotype endorsement, perceived discrimination and social withdraw) correlated with stigma experiences and total stigma score, but did not correlate with discrimination experiences, except for stereotype endorsement domain.

1.3.2 Psychometric properties

Summarizing what was previously mentioned, CESQ is the most studied scale that only measures experience of stigma.[30]

Psychometric properties and compliance with general criteria defined by Terwee at al. for measurement properties of health status questionnaires are as follows:

- Content validity was reported by Wahl et al.[29], and meets Terwee criteria.
- Criterion validity – there are no studies measuring CESQ against other stigma measures in the literature.
- Construct validity – it has been established by Dickerson et al. and replicated by Switaj et al., regarding the stigma section. There were no correlations found of the stigma subsection with psychiatric symptoms or general functioning, but there was a negative association between stigma and age of becoming ill[68] and stigma and quality of life[35,68,70].
- Internal consistency – Cronbach’s alpha was assessed in stigma subscale (α=0,79)[68,70] In discrimination subscale, alpha reported is 0.63[70]. Factor analysis was done only in

stigma subscale.[70] There are no studies, to the best of our knowledge, reporting assessment of alpha for the whole scale.

- Floor/ ceiling effects – CESQ fails the criteria in all of the studies mentioned.[29,30,35,68–70]
- Test retest reliability has not been reported in the literature.

2 ORIGINAL STUDY

2.1 AIMS

To explore the experience of stigma in a Portuguese sample of people with severe mental illness.

To contribute to the assessment of psychometric properties of Consumer Experiences of Stigma Questionnaire[29], and to the validation of its Portuguese translation.

2.2 METHODS

2.2.1 Study design

Cross-sectional, descriptive and analytic study.

2.2.2 Samples

Our global sample was composed of three convenience, non-randomized subsamples of patients with severe mental illness.

The first one (ARIA sample) consisted of 60 patients from Associação de Reabilitação e Integração Ajuda (ARIA)[1], an NGO from the Lisbon area that provides services in integration and rehabilitation to people with severe mental illness..[74] Its areas of intervention are vocational training programs and employment. ARIA runs a social firm with protected employment, two residential units and four socioocupational forums.

Subjects were referred by mental health professionals from ARIA.

From those 60 patients, 49 accepted to participate in the studies.

Patients came from several facilities in ARIA, as follows: 29 (59.2%) came from socio-occupational forums, 5 (10.2%) came from social action forum 7 (14.3%) from professional qualification and training facility, and 8 (16.3%) from residential units.

The second subsample (Idanha sample) was composed of 43 inpatients from acute and chronic psychiatric units from Casa de Saúde da Idanha, Sisters Hospitallers[75], a psychiatric clinic located in Belas, near Lisbon. Forty two accepted to participate: nine patients (21.4%) from Acute Inpatient Unit and 33 patients from units 3 and 4, which houses prolonged evolution patients.

The third sample (FAPS sample) was drawn from patients participating in the FAPS study, a study of families of people with psychosis[63,76], and was composed of 32 outpatients.

[1] http://www.ARIA.com.pt

2.2.3 Ethical issues

Patients gave their written informed consent to participation in the study.

Permission was obtained for this study, from the ARIA Board of Directors and from the Board of directors and ethics committee in Casa de Saúde da Idanha. Ethics committees had also authorized data collection for the FAPS study.

Confidentiality was fully assured. All the information was processed anonymously and demographic and clinical data were stored separately from identification data, only accessible to the investigator.

2.2.3.1 Inclusion and exclusion criteria

Inclusion criteria were:

- Patients with history, according to International Classification of Diseases 10 (ICD 10)[77] of
    - Schizophrenia, (F20)
    - Schizoaffective disorder (F25)
    - Delusional disorder (F22)
    - Bipolar disorder, manic episode with psychotic symptoms (F 31.2)
    - Bipolar disorder, depressive episode with psychotic symptoms (F31.5)
    - or Major depressive disorder with psychotic symptoms (F32.3)
- Patients should be clinically stable (in order to be able to stand for evaluation).

ICD-10 definitions of the disorders are listed in Annex 1.

2.2.4 Instruments

2.2.4.1 Demographic and Clinical Data

Demographic data collected was:

- age,
- gender,
- marital status,
- current living situation
- current employment status

Clinical data collected was:

- psychiatric diagnosis
- age at onset of illness
- duration of illness

Clinical data was collected by direct reporting of patients and completed by looking through clinical files.

2.2.4.2 Consumer Experiences of Stigma Questionnaire (CESQ)

The Portuguese version of CESQ adopts the Dickerson et al.[35] adaptation of the Wahl's original scale.[29] Its translation was made by Gonçalves-Pereira,[71] as authorized by the original author. Otto Wahl also checked a back-translation by a professional translator who was an English native, fluent in Portuguese and acquainted with the mental health field of research. This translation is available upon request.

For the present study, the Portuguese version of CESQ was discussed with mental health professionals from the institutions where the samples were collected, as for pertinence and phrasing of questions and adaptation to Portuguese reality.

Mental health professionals had the unanimous opinion that item "Have you been excluded from volunteer or social activities in mental health field when it was known you had received psychiatric treatment?" was not applicable to the Portuguese reality.

Moreover, a pilot study was run and we found that participants did not respond to that item, and even found it confusing. Thus, we did not consider it for this study.

The Portuguese translation of CESQ is suitable both for face-to-face or self-report administration. It has two subsections:

- Stigma subscale – nine items - as detailed in Results (Table 6) - about people's interpersonal experiences as "consumers". Those questions are about topics such as specific treatment by others, negative things seen and fears of behaviours related to disclosure of status by consumers. Each experience is rated on a 5-point Likert scale, ranging from "never" to "very often". Participants had the option to state that the item did not apply.
- Discrimination subscale – eleven items - as detailed in Results (Table 7) which intend to explore experienced discrimination in activities such as getting a renting an apartment, applying for a job, volunteering, or obtaining a license, as well as an item concerning avoidance of disclosure of a service user's status in applications. This section is also rated on a 5-point Likert scale, ranging from "never" to "very often". Participants also had the option to state that the item did not apply.

Items were scored 1 (never) to 5 (very often), with the exception of Items "Were friends understanding and supportive after learning that you receive psychiatric treatment?", Have you been treated fairly by others who knew you received psychiatric treatment ?, "Have co-workers and supervisors at work been supportive and accommodating when they learned that you received psychiatric treatment?" and "Have you been treated with kindness and sympathy by law enforcement officers when they learned you had received psychiatric treatment?" which were reversely coded. We followed the principle, by Dickerson et al. of using a "Does not apply" option. When "does not apply was chosen, responses were scored as "0", for the purpose of computing the scores.[35,68] Scores of the sections were computed adding the values for each item. .

In order to assess test-retest reliability, the scale was given to the patients in the ARIA subsample and its administration repeated within one to three weeks in all of those participants who accepted to do so.

2.2.4.1 Global Assessment of Functioning (GAF)

The Global Assessment of Functioning scale has its roots in the Health Sickness Rating Scale (HSRS), published in 1962. Studies regarding HSRS originated Global Assessment Scale (GAS). Further development of GAS led to GAF.

GAF was implemented in 1987, in the Axis V of the Diagnostic and Statistical Manual 4th edition[78]. It measures individual functioning, regarding psychological, social and occupational domains. It is a numerical scale. It is rated from 1 to 100, thus there are 100 scoring possibilities. The scale is divided in intervals, or sections, each one with ten points.

There are a few limitations regarding validity of GAF, mostly regarding its scoring, intervals and anchor points[79].However, it has been shown to have good inter-rater reliability[80] and still remains as the most used measure of functioning.[81]

GAF score was assessed in Idanha and FAPS subsamples.

2.2.5 Statistical Analysis

The data collected for the present study was analysed with the employment of several statistical techniques and methodologies. We present an exploratory data analysis where descriptive statistics, parametric (t-test, one-way ANOVA, chi-square test) and non-parametric (Mann-Whitney, Kruskal-Wallis) tests were used as required. Each statistical test assumptions were verified and the results and outcomes as well as several graphs are presented in the Annexes. Continuous variables were also assessed for normality, using either the Kolmogorov-Smirnov test or the Shapiro-Wilk test (the latter used when the size of the sample being analysed was less than 50).

Patients' characteristics are presented as frequencies and percentages for categorical data, and as mean or median, standard deviation (SD), range and minimum/maximum values for continuous variables. The 95% confidence intervals (CI) for the mean values were calculated and presented whenever appropriate.

The scale was tested for internal consistency using Cronbach's alpha and exploratory factor analysis. The ideal value for Cronbach's alpha was considered to be at least 0.7.[82]

Principal component analysis was primarily used to conduct an exploratory factor analysis to inspect the structure of the CESQ questionnaire by examining its components (afterwards called factors) and investigate whether the presence of the two domains (stigma and discrimination) could be identified.

The aim of factor analysis in the present context was to determine empirically whether the participants' responses to the stigma domain questions were more similar to each other than their responses to the discrimination items, and vice versa. It is, consequently, an exploratory factor analysis on the CESQ scores, as the objective is to seek to describe, and summarize, data by grouping together variables/items that are correlated.

In order to verify the appropriateness of the factor analysis, three techniques were used for the assessment of the psychometric adequacy of the correlation matrix. They were the Bartlett's test of sphericity, evaluating the hypothesis that the correlation matrix is an identity matrix, that is, that there is no correlation amongst the items; rejection of this hypothesis suggests that the data are appropriate for the factor analysis procedure. The second technique was the inspection of the off-diagonal elements of the anti-image correlation matrix, this contains the negatives of the partial correlation between pairs of variables with effects of other variables removed, enabling the quantification of individual measures of sampling adequacy (MSA) and to conclude that the correlation matrix is factorable whenever the absolute values of most of those elements are small (see Tabachnick and Fidell[83] for more details).

The Kaiser-Meyer-Olkin (KMO) statistic was the third technique to be used. This corresponds to an overall MSA that varies between 0 and 1. According to Tabachnick and Fidell[83], values of 0.60 and above are required for a good factor analysis.

Sample size must be sufficient to cope with the rigorous of factor analysis. However, there is much debate about what the minimum limit should be (see Mayers[82] for a discussion). With this data a ratio of 6:1 was obtained and, as it corresponds to a reasonable value, the criterion was met.

Two factors were chosen because there was interest in verifying whether the questions in this questionnaire showed evidence of the presence of the two latent factors (i.e. stigma and discrimination).

The varimax rotation technique with Kaiser normalization was employed. It was postulated that factor loadings presented should be greater than 0.40. In case of several loadings greater than 0.40 for a particular item, that item should be used on the factor with the highest loading.

Intraclass correlation coefficients (ICC) were calculated, using a two-way mixed effects model, where people effects are random and measures effects are fixed.[84]

The 95% confidence intervals for the Cronbach alphas were obtained through the "psychometric" package of the R statistical software.[85,86].

All other analysis were performed through IBM Statistical Package for Social Sciences (SPSS) version 22.[87]

3 RESULTS

3.1 SUBJECTS

Initially 135 participants were screened as eligible in a sample collected on each of the three subsamples- (60 in ARIA, 43 in Idanha and 32 in FAPS).

From those, an overall total of 122 participants (49 from ARIA, 42 from Idanha and 31 from FAPS) accepted to participate in the study.

3.2 SOCIO-DEMOGRAPHIC AND CLINICAL CHARACTERISTICS OF PARTICIPANTS

Frequencies and percentages for the several variables characterising the participants are displayed in Table 3.

Table 3 Socio-demographic characteristics of the participants

n		122
Gender	Female (%)	54 (44.3%)
	Male (%)	68 (55.7%)
Age (years)	Mean (95% CI):	44.9 (42.54,47.26)
	SD:	13.004
	Range	18-96
Marital status	Single (%)	98 (80.3%)
	Married / Living together (%)	9 (7.4%)
	Divorced / Widow (%)	15 (12.3%)
Living status	Living in the community alone (%)	18 (14.9%)
	Living in the community with family support (%)	63 (52.1%)
	Homeless (%)	1 (0.8%)
	Living in an institution (%)	39 (32.2%)
Occupational status	Unemployed / Retired (%)	99 (82.5%)
	Employed / In professional training (%)	21 (17.5%)
Local	ARIA Idanha FAPS	60 (44.8%) 43 (32.1%) 31 (23.1%)

From the overall total of the 122 participants, only five (4.2%) were more than 65 years old. The gender proportion was balanced.

The majority of the participants (80.3%) were single (never married), and eighty two (67.8%) were living in the community, while thirty nine (32.2%) were living in an institution.

The three subsamples were significantly different regarding several of the variables. Concerning gender ($p<0.001$) most participants in Aria and FAPS were males (73.5% and 83.9%, respectively) whereas in Idanha women participants were 85.7% of that subsample (see Table 9 in Annex 5). We compared two categories of living status, i.e. living in the community or living in an institution. The majority of patients in ARIA (89.6%) and in FAPS subsample (100%) were living in the community whereas the highest percentage of patients from Idanha (81%) were living in an institution ($p<0.001$). However, there was no evidence of association ($p=0.156$) between being part of one of either of the three subsamples and the occupational status (unemployed/retired and employed/professional training).

Since the age of the participants registered in Idanha was not normally distributed ($p=0.003$) (Figure 1) the non-parametric Kruskal-Wallis was employed to test whether the participants' age median values were equal on the three locations. It was found that the median ages differed on the three locations ($p<0.001$). In the Idanha subsample, participants tended to be older. (Figure 2)

Detailed socio demographic data regarding the samples is showed in Table 9 (Annex 5).

Clinical characteristics of the participants are listed in Table 4. They are detailed, concerning each of the subsamples in Table 10 (Annex 5)

We were only able to collect data on diagnosis from 87 participants. Schizophrenia (ICD 10 F20) was the most predominant diagnosis, accounting for 67.8% of the total cases.

The non-parametric Mann-Whitney test was employed as the reported age of diagnosis does not seem to follow a Normal distribution (Shapiro-Wilk, $p<0.001$ and $p=0.007$ for the ARIA and IDANHA subsamples, respectively). (see Figure 3) No significant differences were found (Mann-Whitney test, $p=0.211$) on the median values of age of diagnosis on the two subsamples (see Figure 4 for box plot.)

Table 4 - Clinical characteristics of the sample

		n	%
Diagnosis	Schizophrenia (F20.0)	59	67,8
	Bipolar disorder (F31)	12	13,8
	Schizoaffective disorder (F25)	8	9,2
	Depression (F32.3)	6	6,9
	Delusional disorder (F22)	2	2,3
	Total for diagnosis	87	100
Reported age at onset of illness (years)	Mean	23.95	
	SD	8.540	
	Range	11-57	
Reported duration of illness (years)	Mean:	21,00	
	SD:	13.116	
	Range	2-77	

Global Assessment of Functioning (GAF) Score	Mean	42.85
	SD	14,820
	Range	21-75
	Total n for GAF score	73

The participants' duration of illness followed a Normal distribution on the three subsamples (Shapiro-Wilk tests with p=0.071, p=0.052 and p=0.164, for ARIA, IDANHA and FAPS, respectively). The variances of the illness durations could also be considered equal (Levene test, p=0.172). Consequently, a one-way ANOVA procedure was used to compare the mean values of the illness duration on the three locations. The null hypothesis of equality of mean values was rejected (p<0.001). Through multiple comparisons technique, namely Tukey HSD and Sheffe, it was found that the illness duration of participants from IDANHA differed from the other two subsamples (p<0.001). There was no reason to believe that participants in ARIA and FAPS had different mean values of illness duration (Tukey HSD test, p=0.709). Please also refer to page 56.

3.3 RESPONSES TO THE CESQ STIGMA SECTION

Responses to the stigma section are listed in Table 6.

We will follow, after Wahl[29] and Switaj[68], the principle that only experiences reported at least sometimes by all participants are worth noting in the description of results.

Being in situations where one hears others say unfavourable or offensive things about persons and their psychiatric disorders is the most reported negative experience. A majority (64.5%) of the participants say they experienced it at least sometimes, while 28.9% say they have experienced at least often.

More than 62% of the respondents say they are at least sometimes worried that others will view them unfavourably because they received psychiatric treatment, as 33.9% report it happened often or very often.

Avoiding telling others outside the family they have received psychiatric treatment is the third most reported negative experience 52.5% report it at least sometimes and 28% at least often.

Fifty percent of the participants feels sometimes, often or very often treated by others as less competent, and people report that, at least sometimes, they have been told to lower expectations in life. Forty seven percent of the participants reported that, at least sometimes, have been shunned or avoided by others. Forty six percent report that, at least sometimes, they see depictions of mental illness in media they find hurtful or offensive.

Positive experiences are also reported with high frequency: Seventy eight percent of the participants consider that, at least sometimes, friends were understanding and supportive after learning they had received psychiatric treatment, and 77.3% of the participants feel at least sometimes treated fairly by others.

3.4 RESPONSES TO THE CESQ DISCRIMINATION SECTION

Responses to discrimination subscale items are listed in Table 7.

Discrimination experience frequencies were significantly lower than stigma experiences.

Nevertheless, 43.5% of the respondents state that, at least sometimes, have avoided indicating on written application that they received psychiatric treatment for fear that information would be used against them.

Forty one percent of the respondents report that they never or seldom have been treated with kindness and sympathy by law enforcement officers when they learned they had received psychiatric treatment.

Thirty nine percent of the participants say that, at least sometimes, they have been turned down for a job, for which they were qualified, when it was learned they had been receiving psychiatric treatment.

3.5 COMPUTED SCORES AND EXPLORATORY ANALYSIS

Histogram of frequencies of computed scores regarding Stigma Section, Discrimination Section and Total of the scale scores are shown in Figure 18, Figure 20, and Figure 22, in Annex 4.

Table 5 displays descriptive statistics for scores of the scale total (CESQ Total score) and Stigma and Discrimination subscales. Box plots for CESQ total score and gender, occupational status, institutionalization and marital status are shown in Figure 6, Figure 7, Figure 8 and Figure 9. Figure 10, Figure 11, Figure 12 and Figure 13 show Stigma score and each of the latter variables. Figure 14, Figure 15, Figure 16 and Figure 17 show discrimination score and gender, occupational, institutionalization and marital status.

Both CESQ total score, stigma and the discrimination scores followed a Normal distribution (Kolmogorov-Smirnov tests with p=0.200, p=0.098 and p=0.200, respectively). QQ plots of CESQ Total score are shown, respectively in Figure 19, Figure 21 and Figure 23.

Table 5 – Descriptive statistics - Total scores, stigma and discrimination scores

		CESQ Total score	Stigma score	Discrimination Score
Gender mean (SD)	Female	37.8 (12.30)	23.4 (7.39)	14.2 (7.65)
	Male	40.5(11.54)	21.9 (6.42)	18.6 (7.06)
Occupational status mean (SD)	Unemployed / Retired (%)	39.8 (12.24)	23.1 (6.96)	16.75 (7.91)
	Employed / In professional training (%)	37.0 (10.67)	21.0 (6.04)	16.0 (6.54)
Living status mean (SD)	Living in the community	39,9 (11.78)	22.1 (6.25)	17.8 (7.08)
	Living in an institution	37.9 (13.54)	23.7 (8.03)	14.1 (8.27)

Marital status mean (SD)	Single	39.8 (1.19)	22.8 (0.68)	17.0 (0.76)
	Married / Living together	36.2 (5.52)	22.2 (3.53)	14.0 (3.38)
	Divorced / Widow	37.0 (2.55)	21.2 (1.59)	15.8 (1.62)

Table 6- Responses to stigma section

	Never		Seldom		Sometimes		Often		Very often	
	N	%	N	%	N	%	N	%	N	%
Have you avoided telling others outsider of your immediate family that you have received psychiatric treatment?	38	32,2%	18	15,3%	29	24,6%	16	13,6%	17	14,4%
Have you been treated as less competent by others when they learned you had received psychiatric treatment?	36	30,5%	23	19,5%	35	29,7%	15	12,7%	9	7,6%
Were friends understanding and supportive after learning that you receive psychiatric treatment?	12	10,1%	14	11,8%	36	30,3%	38	31,9%	19	16,0%
Have you been shunned or avoided by others when they learned you received psychiatric treatment?	43	35,8%	21	17,5%	36	30,0%	14	11,7%	6	5,0%
Have you been in situations where you heard others say unfavourable or offensive things about persons and their psychiatric disorders?	30	24,8%	13	10,7%	43	35,5%	21	17,4%	14	11,6%
Have you been advised to lower your expectations for accomplishments in life because you receive psychiatric treatment?	47	39,5%	21	17,6%	30	25,2%	15	12,6%	6	5,0%
Have you been treated fairly by others who knew you received psychiatric treatment ?	13	10,9%	14	11,8%	27	22,7%	44	37,0%	21	17,6%
Have you seen or read things in mass media about persons receiving psychiatric treatment and their psychiatric disorders which you found hurtful or offensive?	45	37,5%	20	16,7%	37	30,8%	9	7,5%	9	7,5%
Have you worried that others will view you unfavourably because you received psychiatric treatment?	25	20,7%	20	16,5%	35	28,9%	20	16,5%	21	17,4%

Table 7 - Responses to discrimination section

	Never		Seldom		Sometimes		Often		Very often	
	N	%	N	%	N	%	N	%	N	%
Have you been turned down for a job, for which you were qualified, when it was learned you received psychiatric treatment?	54	50,0%	12	11,1%	23	21,3%	12	11,1%	7	6,5%
Have you been denied psychiatric treatment because your health insurance or healthcare system was insufficient for you to pay the cost?	87	85,3%	4	3,9%	7	6,9%	1	1,0%	3	2,9%
Have you had difficulty renting an apartment or finding other housing when your psychiatric disorder was known?	70	78,7%	6	6,7%	8	9,0%	1	1,1%	4	4,5%
Have you been denied educational opportunities when it was learned that you received psychiatric treatment?	68	66,7%	12	11,8%	16	15,7%	1	1,0%	5	4,9%
Have you been excluded from volunteer or social activities outside mental health field when it was known you had received psychiatric treatment?	71	69,6%	16	15,7%	12	11,8%	1	1,0%	2	2,0%
Have co-workers and supervisors at work been supportive and accommodating when they learned that you received psychiatric treatment?	11	12,2%	11	12,2%	27	30,0%	23	25,6%	18	20,0%
Have you been turned down for health insurance (or healthcare system) coverage on the basis of your psychiatric treatment history?	66	81,5%	6	7,4%	7	8,6%	2	2,5%	0	0,0%
Have you been denied a driver's license or other kind of permit when it was learned you had received psychiatric treatment?	74	80,4%	5	5,4%	8	8,7%	0	0,0%	5	5,4%
Have you had the fact that you received psychiatric treatment used against you in legal proceedings?	77	77,8%	7	7,1%	4	4,0%	4	4,0%	7	7,1%
Have you been treated with kindness and sympathy by law enforcement officers when they learned you had received psychiatric treatment?	31	31,0%	10	10,0%	21	21,0%	25	25,0%	13	13,0%
Have you avoided indicating on written applications that you received psychiatric treatment for fear that information would be used against you?	50	46,3%	11	10,2%	20	18,5%	11	10,2%	16	14,8%

3.6 CESQ TOTAL SCORE CORRELATES AND ASSOCIATIONS

After making sure the assumptions of Normality and equality of variances for CESQ total for both males and females were met (Kolmogorov-Smirnov tests, p=0.200 and Levene test, p=0.519) a two sample t-test for independent samples showed no significant differences in CESQ total score between female~~)~~ and male participants (p=0.179), and between individuals living in the community and living in an institution (p=0.391).

One way ANOVA showed no significant differences in CESQ total between participants with different marital status (single, married/living together and divorced/widow) p=0,517.

There was a weak negative correlation between CESQ total score and both age (r=-0,288, p=0,001, n=119), and reported duration of illness (r= -0.211, p=0.023, n=116). Figure 24 summarizes the result for age and Figure 25 for reported duration of illness.

A weak positive correlation was also found between CESQ total score and global functioning (r=0,284, p=0,015, n=73). Figure 26 shows this correlation.

No significant correlation was found between CESQ total score and reported age of onset of illness (r= -0.114, p= 0.223, n=117)

3.7 STIGMA SCORE CORRELATES AND ASSOCIATIONS

T-test for independent samples showed no significant differences in the Stigma score between female (M: 23.4; SD 7.39) and male participants (p=0,252), between unemployed and employed individuals (p=0,213) and between individuals living in the community (M: 22.1 SD:6.25) and living in an institution. (p=0,272)

One way ANOVA showed no significant differences in the Stigma score between participants with different marital status (single, married/living together and divorced/widow) (p=0,703).

Moreover the Stigma score was found not to be correlated neither with age (r= -0.121, p=0.189, n=119) nor with reported duration of illness (r= -0.063, p=0.499, n=116).

No significant association was found between stigma score and global functioning (r=0.148, p=0.211, n=73).

No significant correlation was found between stigma score and reported age of onset of illness (r= -0.107, p= 0.253, n=117)

3.8 DISCRIMINATION SCORE CORRELATES AND ASSOCIATIONS

T-test for independent samples showed significant differences in discrimination score between female and male participants (p=0,001). Thus, male participants had a higher mean discrimination score. It also showed a statistically significant difference between discrimination score in individuals living in the community and living in an institution.(p=0,014)

T-test for independent samples showed no significant differences in the Discrimination score between unemployed and employed individuals. (p=0.687)

One way ANOVA showed no significant differences in the Discrimination Score between participants with different marital status (single, married/living together and divorced/widow) (p=0,470).

There was a moderate negative correlation between the Discrimination score and age (r=-0,341, p=0,000, n=119), and a weak negative correlation between Discrimination score and reported duration of illness (r= -0.211, p=0.023, n=116). Figure 27 and Figure 28 illustrate these correlations.

A moderate positive correlation was also found between the Discrimination score and global functioning (ρ=0,344, p=0,003, n=73). Figure 29 pictures this correlation.

No significant correlation was found between the Discrimination and reported age of onset of illness (r=-0,75, p= 0,424, n=117)

3.9 PSYCHOMETRIC PROPERTIES OF PORTUGUESE TRANSLATION

3.9.1 Cronbach alpha

Cronbach's Alpha for the 20 items in CESQ scale was 0,801. 95% CI [0.746, 0.849] Item-total correlations were generally at least moderate, and the squared multiple regression generally confirmed that variance was moderately explained throughout. Cronbach's alpha would not generally benefit from removal of any item. For the Stigma subscale, alpha was 0,754. 95% CI [0.683, 0.815] For the Discrimination subscale, alpha was 0.751. 95% CI [0.680, 0.811]

3.9.2 Factor analysis

Factor analysis was conducted on the data studied in this study. According to Bartlett's test (value = 751.80 and p<=0.001) the correlation matrix was not considered to be an identity matrix and was therefore suitable for further analysis. The KMO statistic was greater than 0.6 - 0.73. The MSA values for all individual items (anti-image correlation matrix) were greater than 0.60 and the absolute values of the off-diagonal were very low. Consequently, the factor analysis seemed appropriate. Table 8 displays the items and factor loadings for the rotated factors, with loadings less than 0.40 omitted to improve clarity.

After rotation the first factor accounted for 19% of the total variance and the second factor accounted for 17%. The two factors accounted for around 36% of the total variance.

Order of the items regarding factor loadings seems to replicate findings by Switáj et al in the first factor.[70]

The first factor seems to index stigma loading most strongly on questions 2 (“Have you been treated as less competent by others when they learned you had received psychiatric treatment?”) 4 (“Have you been shunned or avoided by others when they learned you received psychiatric treatment?”), 5 (Have you been in situations where you heard others say unfavourable or offensive things about persons and their psychiatric disorders?) and 9 (Have you worried that others will view you unfavourably because you received psychiatric treatment?), with loadings in the first column, respectively, 0.715, .775, .754, .747. The second factor, which seemed to index discrimination, was composed of nine items with loadings in column 2 of the table.

Questions “Have you avoided telling others outsider of your immediate family that you have received psychiatric treatment?”, “Were friends understanding and supportive after learning that you receive psychiatric treatment?”, “Have you been treated fairly by others who knew you received psychiatric treatment ?” and “Have you been denied psychiatric treatment because your health insurance or healthcare system was insufficient for you to pay the cost” seem not to fit in any of the factors in the model.

Table 8 - Factor loadings for the rotated factors

	Factor loadings		
	Stigma	Discrimination	Communalities
Have you avoided telling others outsider of your immediate family that you have received psychiatric treatment?			0,072
Have you been treated as less competent by others when they learned you had received psychiatric treatment?	0,715		0,512
Were friends understanding and supportive after learning that you receive psychiatric treatment?			0,033
Have you been shunned or avoided by others when they learned you received psychiatric treatment?	0,775		0,602
Have you been in situations where you heard others say unfavourable or offensive things about persons and their psychiatric disorders?	0,754		0,571
Have you been advised to lower your expectations for accomplishments in life because you receive psychiatric	0,623		0,41

treatment?			
Have you been treated fairly by others who knew you received psychiatric treatment ?			0,117
Have you seen or read things in mass media about persons receiving psychiatric treatment and their psychiatric disorders which you found hurtful or offensive?	0,647		0,435
Have you worried that others will view you unfavourably because you received psychiatric treatment?	0,747		0,562
Have you been turned down for a job, for which you were qualified, when it was learned you received psychiatric treatment?		0,403	0,285
Have you been denied psychiatric treatment because your health insurance or healthcare system was insufficient for you to pay the cost?			0,094
Have you had difficulty renting an appartment or finding other housing when your psychiatric disorder was known?		0,521	0,271
Have you been denied educational opportunities when it was learned that you received psychiatric treatment?		0,633	0,459
Have you been excluded from volunteer or social activities when it was known you had received psychiatric treatment?		0,661	0,518
Have co-workers and supervisors at work been supportive and accomodating when they learned that you received psychiatric treatment?		0,635	0,428
Have you been turned down for health insurance coverage or for a loan on the basis of your psychiatric treatment history?		0,782	0,622
Have you been denied a driver's license or other kind of permit when it was learned you had received psychiatric treatment?		0,591	0,377
Have you had the fact that you received psychiatric treatment used against you in legal proceedings?		0,509	0,346
Have you been treated with kindness and sympathy by law enforcement officers when they learned you had		0,431	0,185

received psychiatric treatment?			
Have you avoided indicating on written applications that you receives psychiatric treatment for fear that information would be used against you?	0,441		0,306
Eigenvalues	3,790	3,414	
% of variance	18,951	17,072	

3.9.3 Test-retest reliability

Test-retest reliability was assessed for 48 participants. The ICC for the CESQ total score was 0.825 (95% CI of 0.709 to 0.898, $p<0.001$), while for the subscales/domains the ICCs obtained were: 0.833 (95% CI of 0.721 to 0.903, $p<0.001$) for stigma and 0.633 (95% CI of 0.430 to 0.775, $p<0.001$) for discrimination.

4 DISCUSSION

4.1 IMPORTANCE OF THE STUDY

To reduce stigma and discrimination is an increasingly recognized key objective in mental health policies around the world, and it has been the object of several programmes aimed specifically for that purpose.[10,88]

Patient- reported outcome measurements have gained an important role and are rapidly becoming the mainstay of outcome measurement, both at interventions level[89] and in quality improvement models.[90].

By turning stigma and discrimination into something measurable, one can more objectively assess the efficacy of interventions to tackle them both at national, regional and local level. Examples of these assessments of interventions include studies by Hansson and Markström[91] and by Campos et al.[61].

By measuring the personal experience of stigma in people with mental illness, one can make more comprehensive assessments, including the service users' perspective.

Focusing on mental health services research, if we applied Donabedian's framework of structure, processes and outcomes[92] to stigma, the experience of stigma could, thus, be viewed as a patient reported outcome measurement. Hence, it is extremely important both to provide assessments of stigma according to the service users' perspective and also to develop psychometric instruments that can feasibly measure the experience of stigma at both international and national levels. That were precisely the aims of our study.

Previous studies of stigma in Portugal are different from current study.

Some of the researchers study the potentially stigmatizing group – in other words, the general population, or subgroups within it, regarding several public stigma domains:

- Loureiro et al. researched attitudes and behaviour in the general population[55] and mental health literacy in a specific group of the general population (adolescents and young adults).[55,57,93]
- Palha, Campos et al. also focused on mental health literacy in adolescents, by studying interventions designed to improve it. [60] They also assessed attitudes towards mental illness in a population of university students.[59,88]
- Chambers, Botelho et al. study attitudes towards mental illness in a sample of mental health nurses.[62]

The population in our study belongs to a group that is stigmatized rather than stigmatizing. In other words, we have studied personal stigma rather than public stigma.

Gonçalves-Pereira et al. studied, among other variables, stigma in the caregivers of patients with schizophrenia.[63] - a group that is also stigmatized, but which is different from ours: in fact,

the population in our study is made of people with severe mental illness, instead of their caregivers.

We acknowledge other studies that have specifically researched into stigma in people with mental illness and their personal stigma. The Maristan study measured self stigma, perceived discrimination regarding mental health professionals, and patients' perceptions on mental health services and informal networks.[48] However our study measures variables in a different domain, according to Brohan et al.'s categorization[30] – actual experiences of stigma and discrimination. Sousa et al.[65] studied the relationship between self-stigma and recovery potential in schizophrenia. Participants had moderate scores in experiences of discrimination subscale in ISMI. However, ISMI is not specific to experiences of stigma, measuring mainly self-stigma constructs.[30]

In sum, we approached stigma in a different manner. In order to do so, we used CESQ, the most well-known scale that measures experiences of stigma at international level, according to the revision by Brohan et al.[30].

4.2 Discussion of CESQ scoring Results

In our results, CESQ stigma subscale items were highly scored in general, with the majority of patients having stigmatizing experiences at least sometimes. We should also note the relatively high reported frequencies of items describing positive experiences. The most reported negative experience was being in situations where one hears other people saying unfavourable things about people with mental illness. The second most reported stigma experience was being worried about other people's opinion after they have learned the respondent had received psychiatric treatment.

The high frequencies of these reports of the experience of stigma suggest that public stigma against mental illness is still rooted in Portuguese society and triggers stigmatizing behaviours perceptible to patients.

Positive experiences are also worth noting: 78% of the participants consider that, at least sometimes, friends were understanding and supportive after learning they had received psychiatric treatment and 77% of the patients feel that others treat them fairly.

The high prevalence of both positive and negative experiences can well correlate with the previous study about attitudes towards mental illness by Loureiro et al.[55], in which public tolerability regarding mental illness was high, but beliefs about dangerousness and incurability persisted.

Reported discrimination experiences' frequency is relatively low. Nevertheless, the fact that more than forty percent of the respondents state that at least sometimes, they have avoided indicating on written application that they received psychiatric treatment for fear that information would be used against them, is, in our opinion, an indicator of the prejudice that still exists in the Portuguese society.

More than forty percent of the respondents report that they never (or seldom) have been treated with kindness and sympathy by law enforcement officers when they learned they had

received psychiatric treatment. In Portugal, in a study in the so-called Metropolitan Psychiatric Emergency in Porto area, 18% of total observed patients in the emergency room have been shown to be involuntary commited.[94]Emergency involuntary commitment has been shown to account for up to 90% of total involuntary commitments in Lisbon area.[95] Law enforcement officers have a very important role in taking people with mental illness to the emergency room for examination by psychiatrists. Therefore, this finding could raise some concerns, as also stated below.

In both stigma an discrimination subscales, frequencies of responses to items were not as high as reported by Wahl[29], possibly due to the fact that Wahl's study is based on a NAMI affiliated sample, perhaps a more empowered group or at least more aware of stigma issues.

Sample in our study comprised patients from both inpatient and outpatient clinics. In that sense, it was more heterogeneous than the one in Dickerson et al.'s study.[35], who recruited patients at an outpatient clinic, and similar to sample from study by Switaj et al.[68] Frequencies in the stigma subscale in our study were grossly comparable to those reported by Dickerson et al.,[35] and Switaj et al.

Our sample tended to report a slightly lower frequency of discrimination experiences, than the sample in the study by Dickerson et. al.[35] That effect is, maybe, attributable to the different provenience of our sample, as discussed below.

4.3 Psychometric properties of Portuguese version of CESQ

Regarding psychometric properties, CESQ was already in compliance with criteria defined by Terwee et al concerning content validity. However, some of its psychometric properties were not yet fully determined: test-retest reliability, criterion validity, and factorial validity.

The Portuguese version of CESQ did not have its psychometric properties documented. In fact, no studies involving the Portuguese version of CESQ had been published until now.

This study aimed to provide a contribution to assessment of psychometric properties of CESQ, as well as those in its Portuguese version, with a special emphasis on reliability measures.

Regarding face and content validity, the Portuguese translation of CESQ was discussed with mental health professionals from ARIA and Casa de Saúde da Idanha, who provided valuable contributions to refinement of translation, wording and phrasing.

Regarding construct validity, results from our study do not replicate exactly previous construct validity data, as we will detail further in this discussion.

In factor analysis most of the items in the questionnaire seemed to fit a two factor model, in line with the original factors. Also, factors with the highest loadings seem to match those obtained by Switaj et al. in their factor analysis of stigma subsection of the scale.[70] Nevertheless, four of the items did not fit in any of the two factors.

Cronbach's alpha of CESQ scale was 0.801. This value for the whole scale is not reported in the literature.

For the stigma subscale, Cronbach's alpha was 0.754, which is comparable to results by Switaj et al.[68]

Regarding the discrimination subscale, Cronbach's alpha in our sample was 0.751. Switaj et al stated that the value for alpha in discrimination subscale in their sample was 0.63.[70] Our value is good[82] and far better than the one obtained by other authors. We do not have a clear explanation for this fact.

Test retest reliability was, for the first time at the international level, assessed in a study using CESQ. Criteria suggested by Terwee et al are an ICC of at least 0.70, measured in a sample of at least fifty patients. Our assessment is only two participants short to meet exactly Terwee sample requirements [31]. However, values for stigma and CESQ total scale obtained were considered acceptable.[31,96] Test retest reliability for discrimination subscale is lower than the limit of acceptability.

We should stress that issues with psychometric properties of the discrimination section were also found in Switaj et al.'s study. However, our sample's Cronbach Alpha regarding that section is better than the one reported by those authors.

4.4 CORRELATES OF STIGMA AND DISCRIMINATION

Regarding computed scores, there was no difference in stigma score or total CESQ score between individuals living in an institution and individuals living in the community.

This seems to be in line with evidence from previous studies using CESQ.[35,68–70]

However, our study found that individuals living in an institution appeared to report a lower discrimination score than individuals living in the community.

Differences in discrimination scores might be related to the fact people in an institution are integrated and more protected from contact with stigmatizing individuals and, thus, from discriminatory experiences than individuals in the community.

Dickerson et al.[35] found no significant association between stigma (or discrimination) scores and degree of community integration. Switaj et al.[68] also found no significant association between the clinical setting and stigma scores.

Although not consistent with this evidence published by those authors, findings from a study by Angermeyer et al.[27]are apparently in line with our result. That study was made immediately after the reform of mental health care in Germany. In that reform, old state psychiatric hospitals were closed and modern university hospitals were built, performing a shift from a custodial to a community based mental health care. As one of the motives of the reform was that patients in psychiatric hospitals experienced more stigma, it was hypothesized that perceived devaluation was higher in patients attending psychiatric hospitals than those attending university hospitals. Unexpectedly, the result was that perceived devaluation was higher in patients attending university hospitals.

A possible explanation to the fact this difference occurs with discrimination score and it does not occur with stigma score or CESQ total score might be the fact that some of the items, such

as “Have you had difficulty renting an apartment or finding other housing when your psychiatric disorder was known?”, “Have co-workers and supervisors at work been supportive and accommodating when they learned that you received psychiatric treatment?” ,“Have you been turned down for health insurance coverage on the basis of your psychiatric treatment history?” or “Have you been treated with kindness and sympathy by law enforcement officers when they learned you had received psychiatric treatment?”

Male gender was apparently associated with higher levels of discrimination experiences, but not of stigma or of CESQ total scores. Previous studies using CESQ failed to document any significant association between these variables. However, in Livingston et al.’s review[23], four of 38 reviewed studies exploring associations between gender and stigma, male patients experienced more stigma than female, while in three of those studies, female patients experienced more stigma than males. We should note that 31 those studies failed to document any significant association. Findings from our study may suggest that mental illness in females is more socially accepted.

Concerning age, we found an apparent weak negative correlation with total CESQ score and an apparent moderate negative correlation with the discrimination score. There seems to be no significant correlation with stigma score. Livingston et al[23] had already pointed the inconsistency of the studies regarding associations between age and stigma.

Reported duration of illness is a variable that is related to age. There appeared to be a weak negative correlation with CESQ total and discrimination scores, but again not with stigma.

Reported age of onset of illness was not significantly correlated with CESQ total score, discrimination or stigma. Hence, this suggests that the correlation of reported duration of illness with stigma scores may be confounded by age.

An hypothetical explanation to the effects of age on CESQ scores would be that as people get older they tend to develop coping mechanisms in order to overcome discrimination, or not to expose themselves so easily to discrimination experiences.

Switaj et al.[68] established an apparent correlation between stigma scores and the age of becoming ill. A possible explanation point by the authors is that “becoming ill at a younger age, when one’s personal circumstances are not quite established and one’s social network is still underdeveloped, might make it difficult to master the resources necessary for avoiding negative social responses or facing up to them, which in turn makes mentally ill people more exposed to rejection”. We apparently found no significant correlation in our study between stigma score, discrimination score, CESQ total score and the latter variable and, thus, we have not been able to replicate their result. We are unable to find explanation for this result.

No association was found between stigma and discrimination scores and employment status, or marital status. This is similar to most of studies in the literature concerning internalized stigma[23] and to previous studies using CESQ.[35,68–70,73]

Studies involving CESQ reported an apparent lack of correlation between experiences of stigma and global functioning [35,68].

Lundberg et al. have reported a moderate inverse correlation between prevalence of devaluation/discrimination and global functioning.[26] Explanations for that finding, according to the same authors, are that being labelled with a mental illness triggers expectations of rejection that may disrupt social interaction and impair social and psychological functioning.

Surprisingly, we found a moderate positive correlation between the discrimination score and global functioning, and a weak positive correlation between CESQ total score and global functioning. Our hypothesis to explain it is that maybe global functioning was associated in our sample with an increased awareness and increased reporting of discrimination experiences. Another possible explanation is the fact that participants with lower global functioning scores tended to live in an institution. These participants, as already mentioned, may be more "protected" from discrimination experiences.

4.5 LIMITATIONS OF THE STUDY

We consider that this study globally met its aims.

However, when applying the CESQ measure after the pilot study, we found that some of the patients had difficulty understanding the questions. None of the questionnaires, however, had missing data. Thus, we can argue that Portuguese translation is comprehensible.

Moreover, our sample was a convenience non-randomized sample, and it was confined to greater Lisbon areas. Differences in the interpretation of items might exist in other regions of Portugal.

Subsamples were heterogeneous and this limited statistical power. There was also an underreporting of diagnosis in the ARIA sample, which prevented better comparisons of CESQ scores among diagnostic groups.

A multivariate analysis should have been done in order to assess if the correlation of reported duration of illness with stigma scores is confounded by age.

Discriminant and convergent validity of CESQ scale was not thoroughly assessed. Other related constructs might be measured besides GAF and constructs within socio-demographic and clinical data.

These issues do not allow generalizability. Thus, results of this study should be taken with caution.

4.6 FURTHER RESEARCH AND IMPLICATIONS OF THE STUDY

This study is the first to explore direct experiences of stigma and discrimination in a Portuguese clinical sample.

Further replications should use larger samples, preferably from multiple regions in Portugal and from multiple settings.

The high frequency of responses to positive experiences in the stigma section, should prompt us to investigate the role of social support/informal care networks in stigma. It would be interesting to apply in the same study both CESQ and a scale that measures these constructs, such as MARISTAN stigma scale.[48]

Also interesting would be to explore relationships between experienced stigma and other related constructs in personal stigma – such as self-stigma and perceived stigma.

Another interesting avenue of research, at the national level, would be to assess covariates between experiences of stigma and its consequences.

Regarding the validity and psychometric properties of the CESQ measure, further work should be pursued in order to test the ecological validity of the translation. Therefore, we think there must be further discussions, preferably within groups of patients, in order to foster adaptations to the Portuguese language and culture.

Other outcomes should be assessed in order to enhance data regarding discriminant and convergent validity of the Portuguese translation. We suggest measuring constructs such as years of schooling, quality of life, general psychopathology and depression.

Although there is no “gold standard” regarding measures of experiences of stigma, it seems also advisable to apply CESQ and other instruments, such as ISMI and DISC that measure the same construct, (apart from other constructs) in order to enhance criterion validity.

Test-retest reliability assessment could be replicated, using a larger sample.

From the services organization standpoint, results of this study, if replicated, might provide a rationale for designing specific interventions in order to tackle stigma, and aim them at selected groups.

For example, involvement of stakeholders within the media might prove important, as more than 40% of the patients report hearing or reading hurtful or offensive depictions of mental illness. Another target group for actions might be law enforcement officers.

As experiences of stigma actually reflect the individual impact of public stigma, CESQ can be explored as an outcome measurement for anti-stigma policies and programmes.

5 CONCLUSIONS

This study provides an insight into levels of experienced stigma and discrimination in Portugal. A majority of patients in our sample had faced, at least sometimes, such experiences.

In our study, discrimination experiences seem to be positively associated to male gender and living in the community and inversely correlated with age and duration of illness. Possible explanations for these associations might be, respectively: better social acceptation of mental illness in females, possible protection of institutionalized patients concerning discrimination experiences and age related development of coping mechanisms to deal with or to avoid discrimination.

There is also an apparent positive correlation between discrimination and global functioning, maybe due to increased awareness and increased reporting of discrimination experiences.

These results prompt research to explore other covariates, such as the role of informal networks.

We also aimed to contribute to the assessment of the psychometric properties of the Consumer Experiences of Stigma Questionnaire-CESQ, using this authorized Portuguese translation. Regarding this, we have successfully assessed test-retest reliability for the first time internationally, obtaining good results. We also confirmed a good internal consistency, and the overall factorial validity of the previously proposed stigma and discrimination subscales.

Thus we provided a valid contribute to the assessment of CESQ psychometrics, completing data concerning its reliability.

Experiences of stigma are, at the individual level, the consequence of public stigma. Therefore, they can be studied as an outcome measurement, when evaluating interventions developed to tackle stigma, both at national and local level.

Further development of tools that measure experiences of stigma, as well as other domains of individual stigma are, thus, crucial for ensuring patients to have the “highest attainable standard of care”, as the Convention on the Rights of People with Disabilities states.[7]

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ANNEXES

1 Disorders' definitions in the International Classification of Diseases - 10^{77}

- ***F20 – Schizophrenia***

  The schizophrenic disorders are characterized in general by fundamental and characteristic distortions of thinking and perception, and affects that are inappropriate or blunted. Clear consciousness and intellectual capacity are usually maintained although certain cognitive deficits may evolve in the course of time. The most important psychopathological phenomena include thought echo; thought insertion or withdrawal; thought broadcasting; delusional perception and delusions of control; influence or passivity; hallucinatory voices commenting or discussing the patient in the third person; thought disorders and negative symptoms.

  The course of schizophrenic disorders can be either continuous, or episodic with progressive or stable deficit, or there can be one or more episodes with complete or incomplete remission. The diagnosis of schizophrenia should not be made in the presence of extensive depressive or manic symptoms unless it is clear that schizophrenic symptoms antedate the affective disturbance. Nor should schizophrenia be diagnosed in the presence of overt brain disease or during states of drug intoxication or withdrawal. Similar disorders developing in the presence of epilepsy or other brain disease should be classified under F06.2, and those induced by psychoactive substances under F10-F19 with common fourth character .5.

- ***F22.0 - Delusional disorder***

  A disorder characterized by the development either of a single delusion or of a set of related delusions that are usually persistent and sometimes lifelong. The content of the delusion or delusions is very variable. Clear and persistent auditory hallucinations (voices), schizophrenic symptoms such as delusions of control and marked blunting of affect, and definite evidence of brain disease are all incompatible with this diagnosis. However, the presence of occasional or transitory auditory hallucinations, particularly in elderly patients, does not rule out this diagnosis, provided that they are not typically schizophrenic and form only a small part of the overall clinical picture.

- ***F25 - Schizoaffective disorders***

  Episodic disorders in which both affective and schizophrenic symptoms are prominent but which do not justify a diagnosis of either schizophrenia or depressive or manic episodes. Other conditions in which affective symptoms are superimposed on a pre-existing schizophrenic illness, or co-exist or alternate with persistent delusional disorders of other kinds, are classified under F20-F29. Mood-incongruent psychotic symptoms in affective disorders do not justify a diagnosis of schizoaffective disorder.

- ***F 31 – Bipolar affective disorder***

  A disorder characterized by two or more episodes in which the patient's mood and activity levels are significantly disturbed, this disturbance consisting on some occasions of an elevation of mood and increased energy and activity (hypomania or mania) and on others of a lowering of mood and decreased energy and activity (depression). Repeated episodes of hypomania or mania only are classified as bipolar.

- ***F33 - Depressive episode***

  In typical mild, moderate, or severe depressive episodes, the patient suffers from lowering of mood, reduction of energy, and decrease in activity. Capacity for enjoyment, interest, and concentration is reduced, and marked tiredness after even minimum effort is common. Sleep is usually disturbed and appetite diminished. Self-esteem and self-confidence are almost always reduced and, even in the mild form, some ideas of guilt or worthlessness are often present. The lowered mood varies little from day to day, is unresponsive to circumstances and may be accompanied by so-called "somatic" symptoms, such as loss of interest and pleasurable feelings, waking in the morning several hours before the usual time, depression worst in the morning, marked psychomotor retardation, agitation, loss of appetite, weight loss, and loss of libido. Depending upon the number and severity of the symptoms, a depressive episode may be specified as mild, moderate or severe.

  - F 32.3 Severe depressive episode with psychotic symptoms

    An episode of depression as described in F32.2, but with the presence of hallucinations, delusions, psychomotor retardation, or stupor so severe that ordinary social activities are impossible; there may be danger to life from suicide, dehydration, or starvation. The hallucinations and delusions may or may not be mood-congruent.

2 EXAMPLES OF ITEMS IN WAHL'S ORIGINAL VERSION[29]

I have worried that others will view me unfavorably because I am a consumer.

I have been in situations where I have heard others say unfavorable or offensive things about consumers and their illnesses.

I have seen or read things in the mass media (e.g., television, movies, books) about consumers and their illnesses that I find hurtful or offensive.

3 EXAMPLES OF ITEMS IN THE VERSION MODIFIED BY DICKERSON ET AL.[35]

Have you avoided telling others outsider of your immediate family that you have received psychiatric treatment?

Have you been treated as less competent by others when they learned you had received psychiatric treatment?

Were friends understanding and supportive after learning that you receive psychiatric treatment?

4 FIGURES

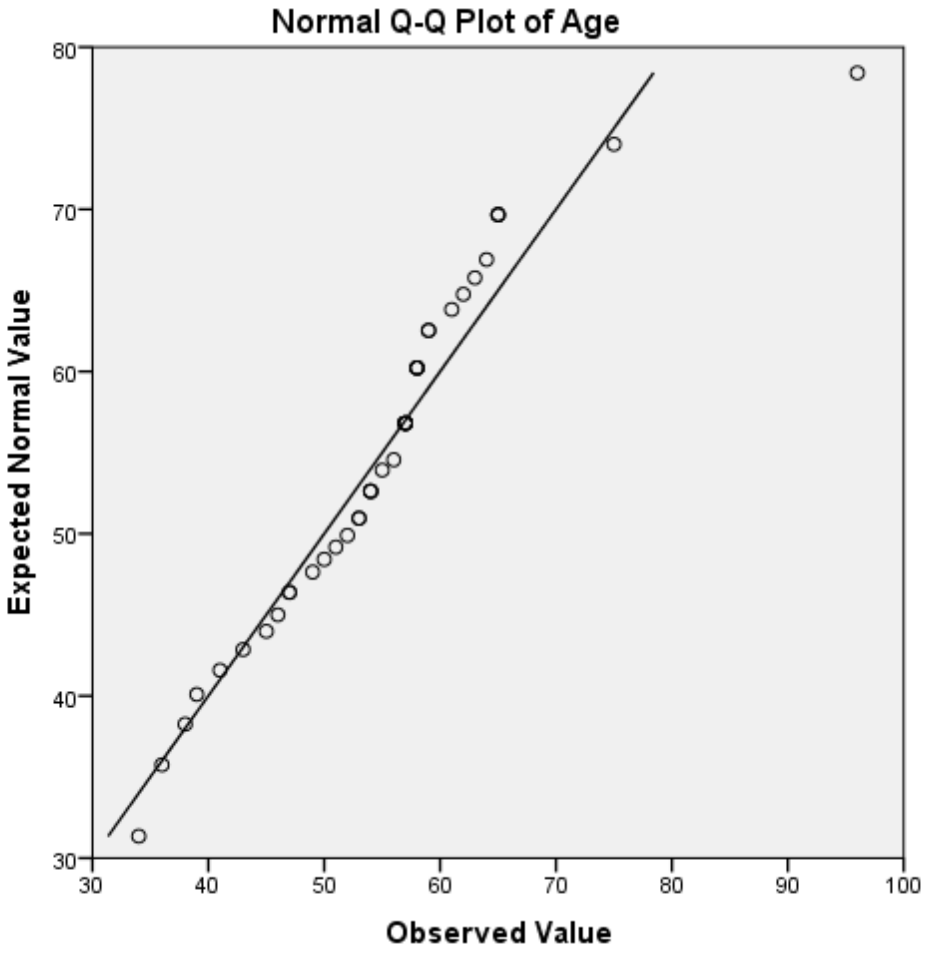

Figure 1 – QQ plot - patient age – Idanha

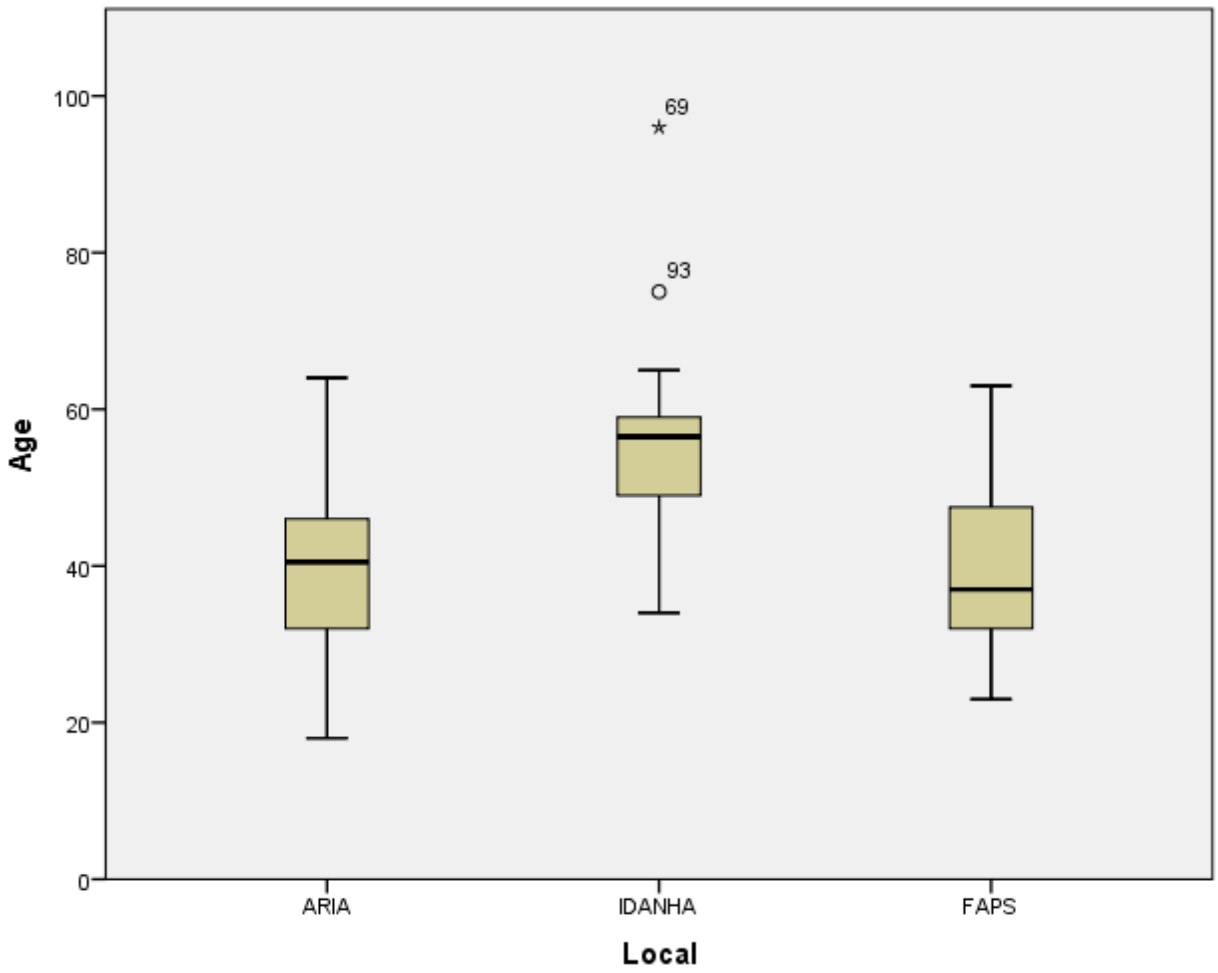

Figure 2 - Box plot - age and local

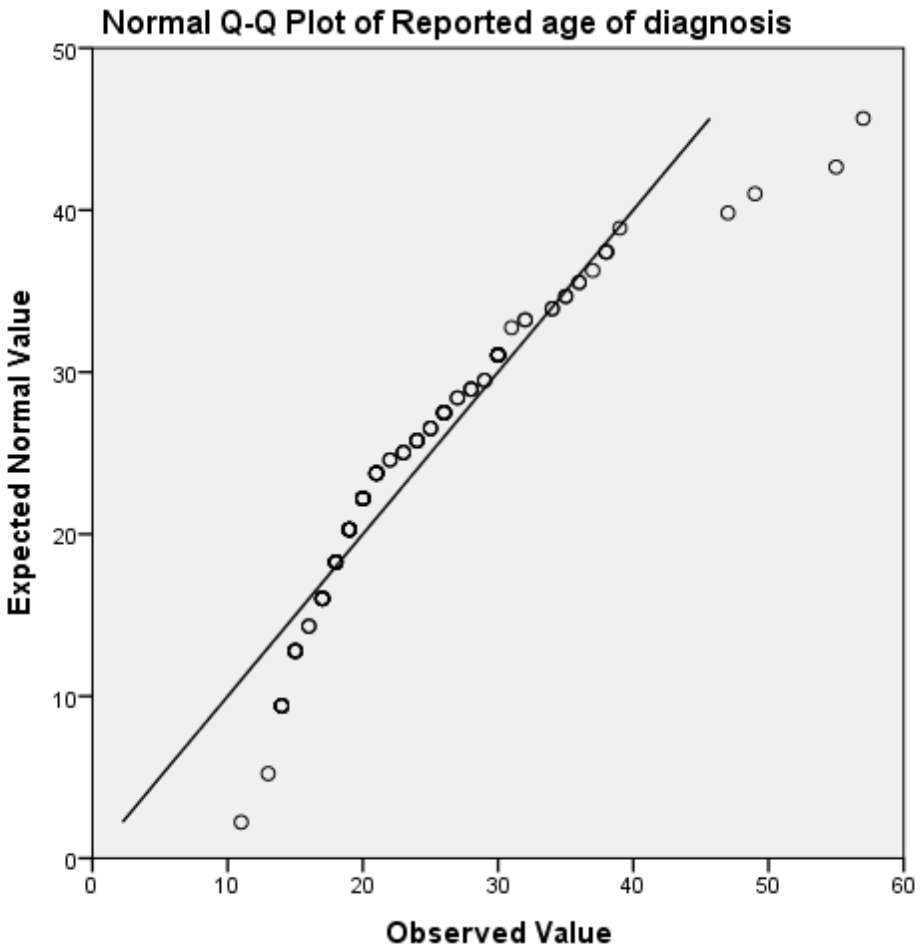

Figure 3 - Reported age of diagnosis

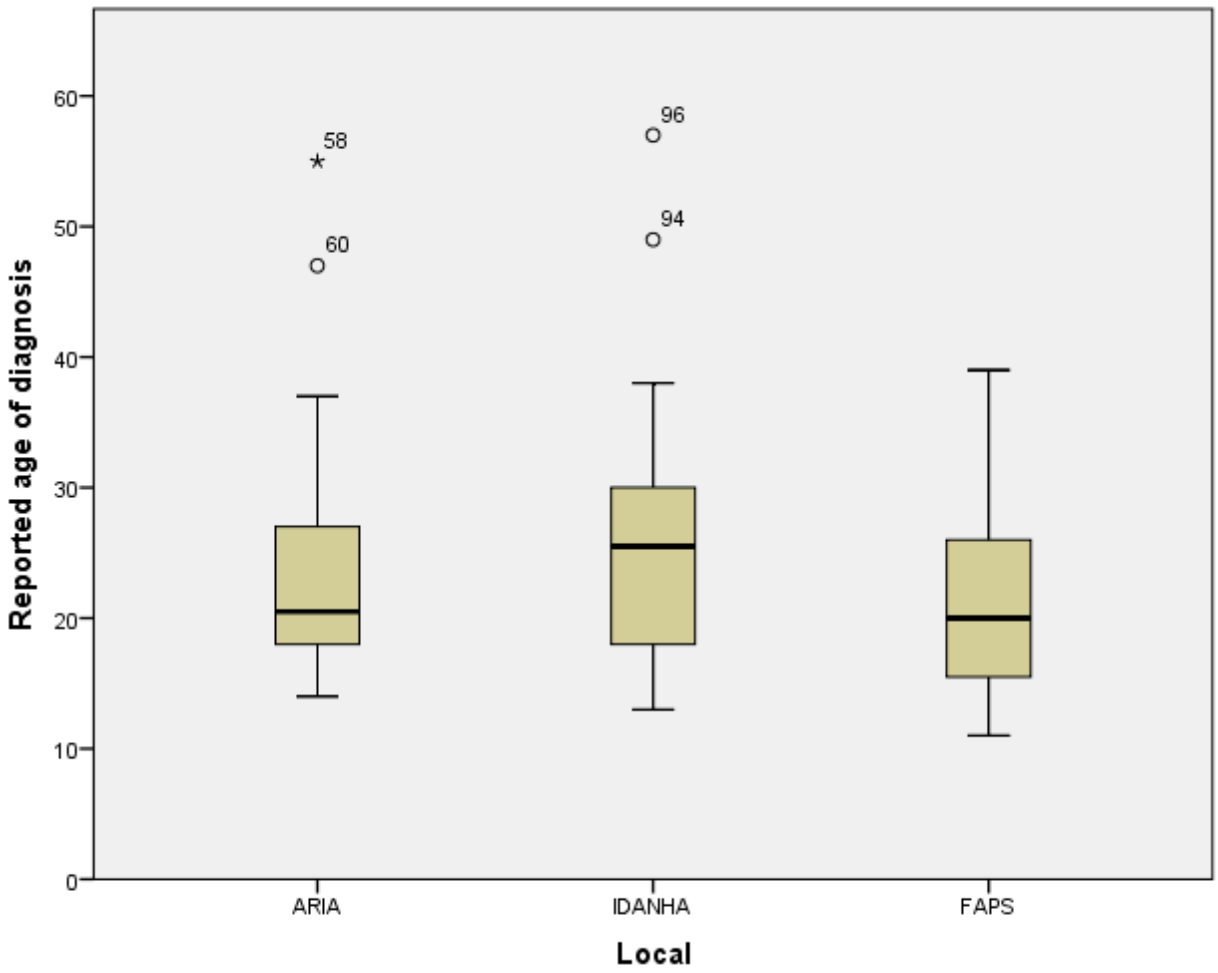

Figure 4 - Reported age of diagnosis by local

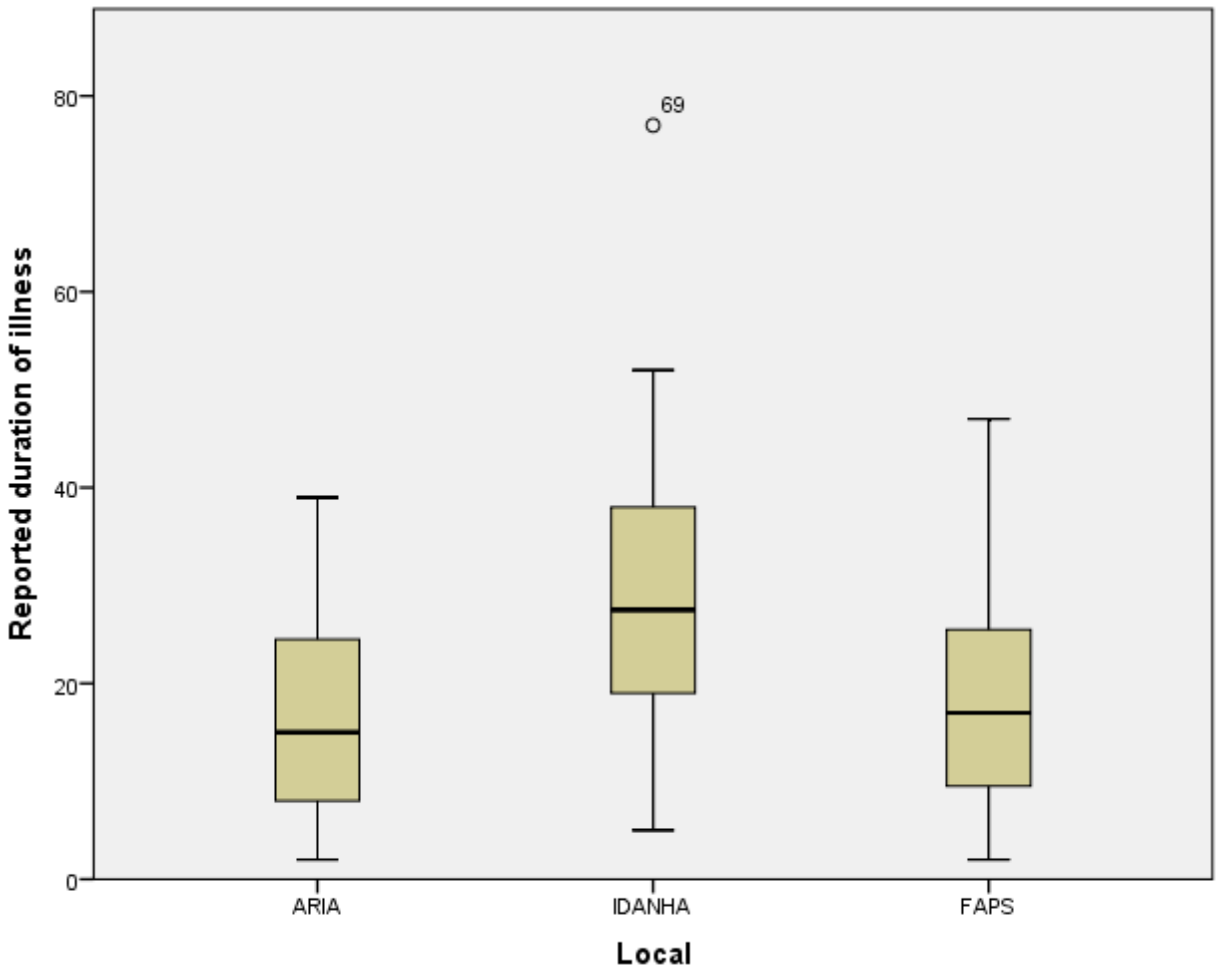

Figure 5 - Reported duration of illness by local

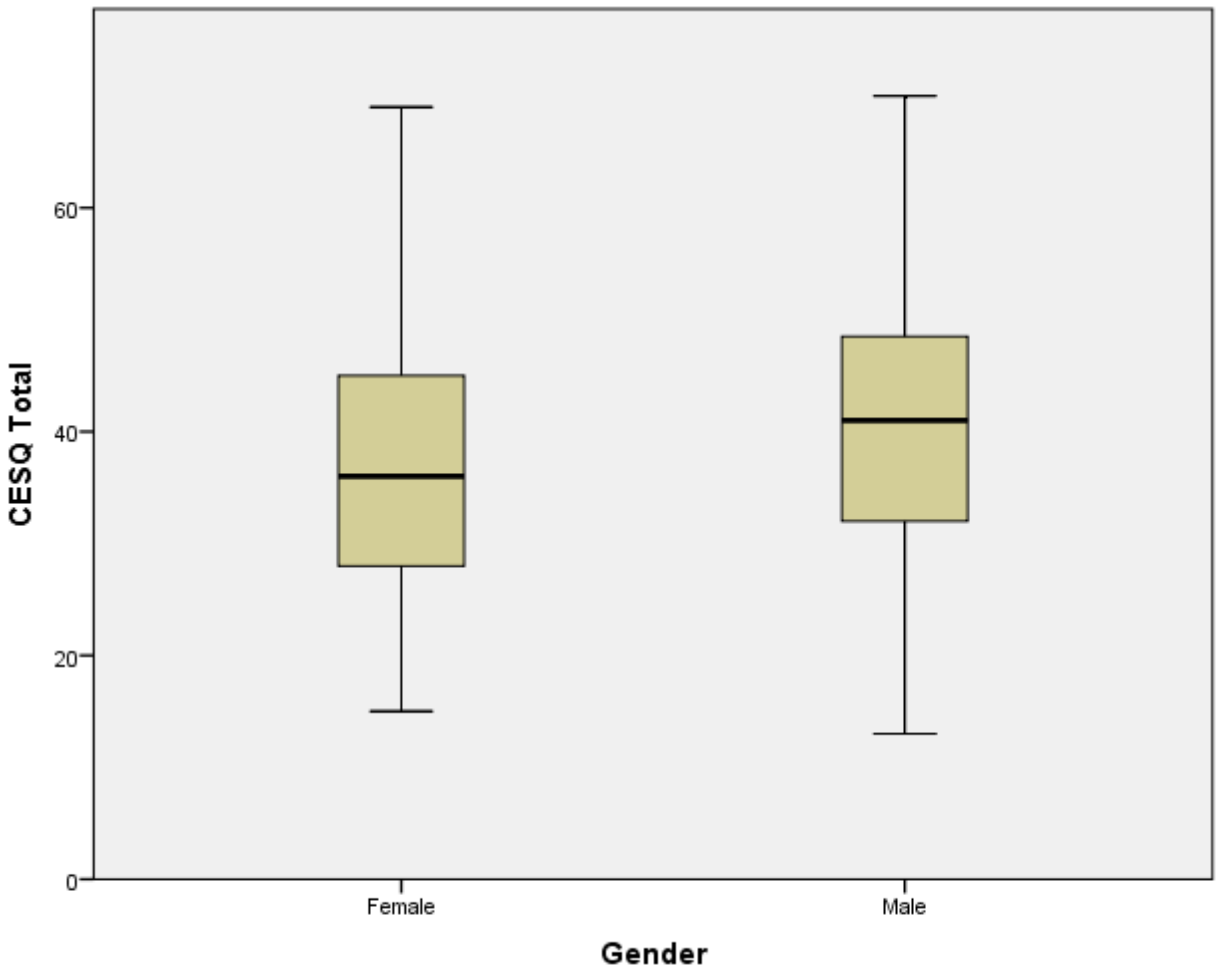

Figure 6 - Box plot - CESQ total and Gender

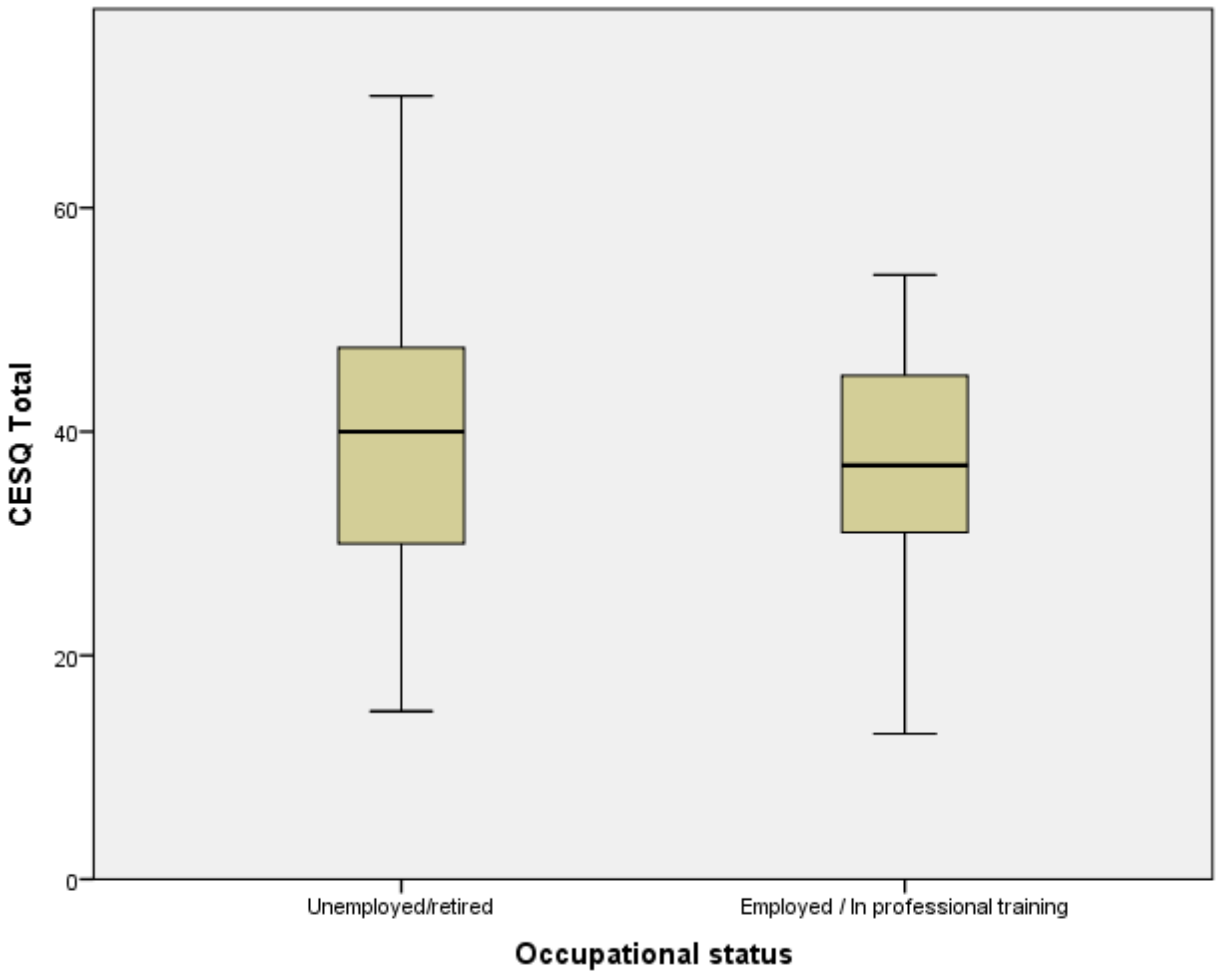

Figure 7 - Box plot - CESQ total and occupational status

Figure 8 - Box plot - CESQ total and institutionalization

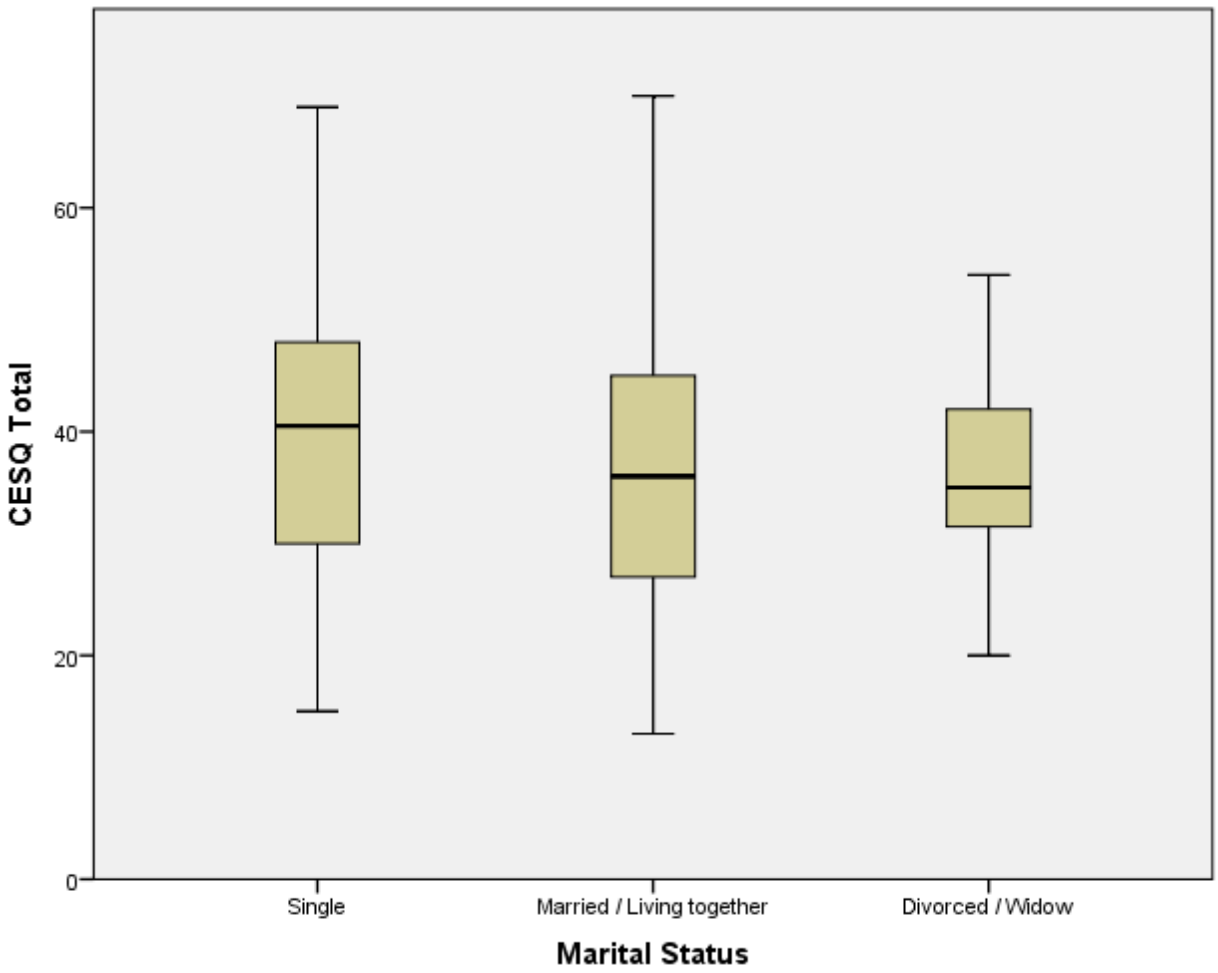

Figure 9 - Box plot - CESQ total and marital status

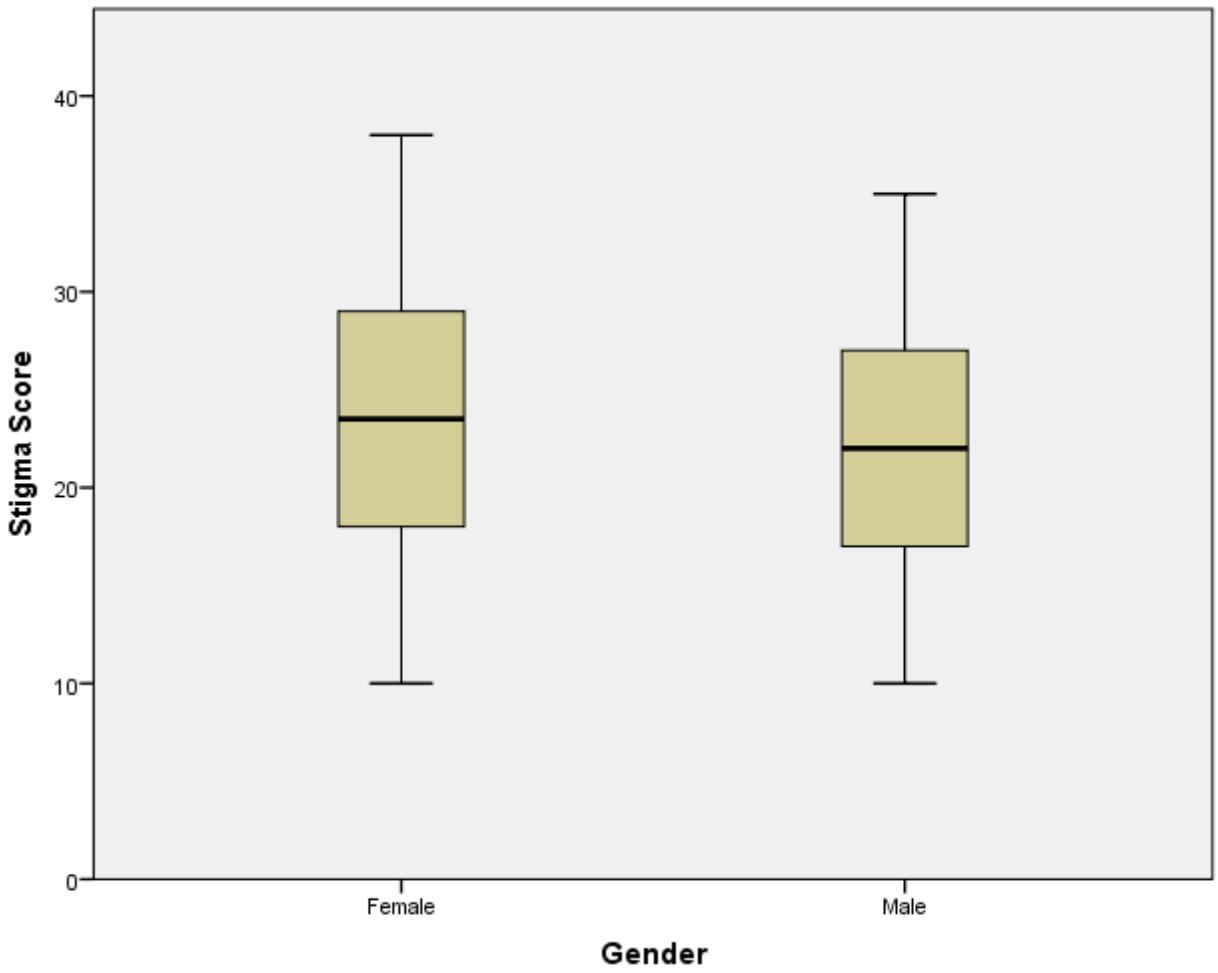

Figure 10 - Box plot - Stigma score and gender

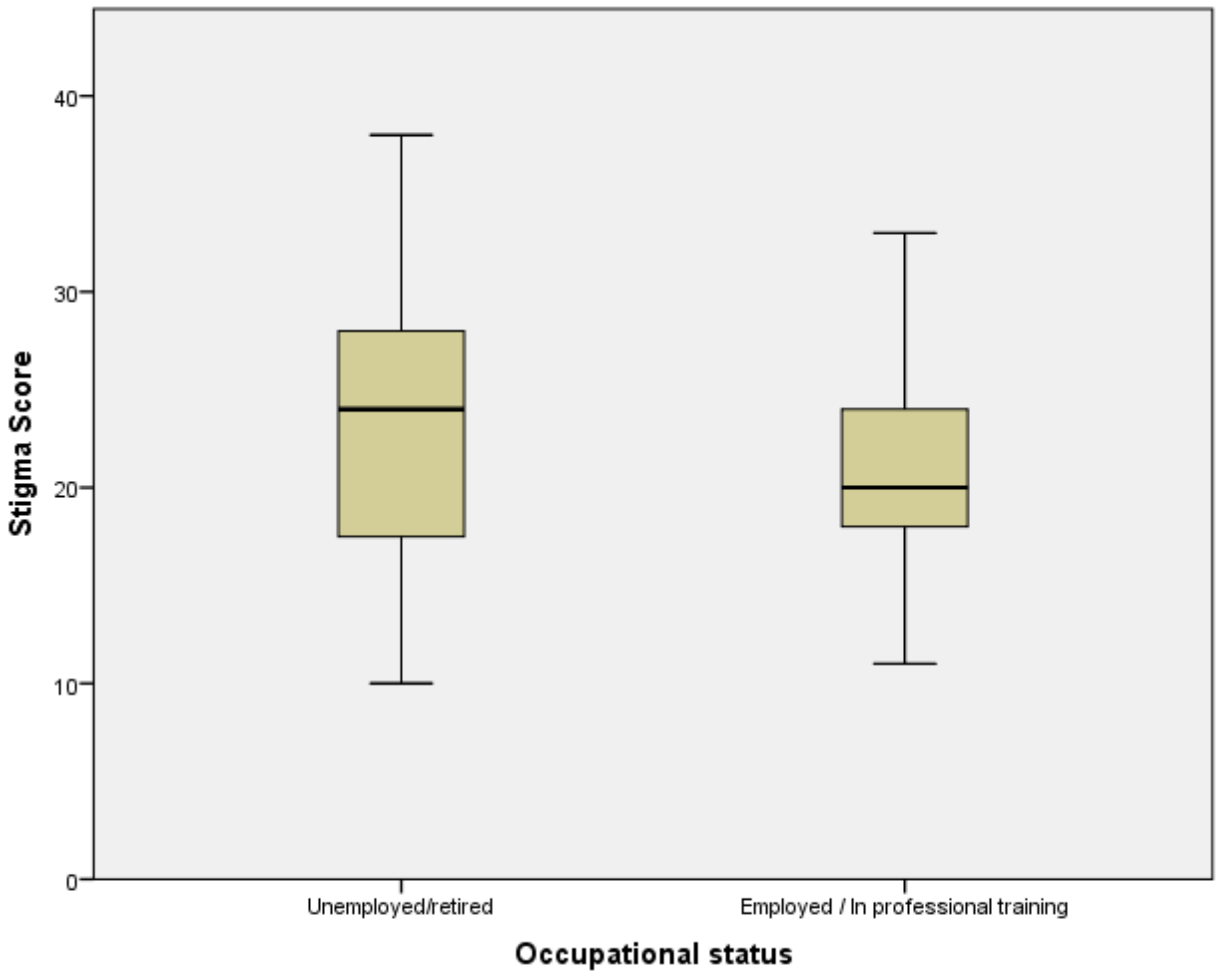

Figure 11- Box plot - Stigma score and occupational status

Figure 12 - Box plot - Stigma score and institutionalization

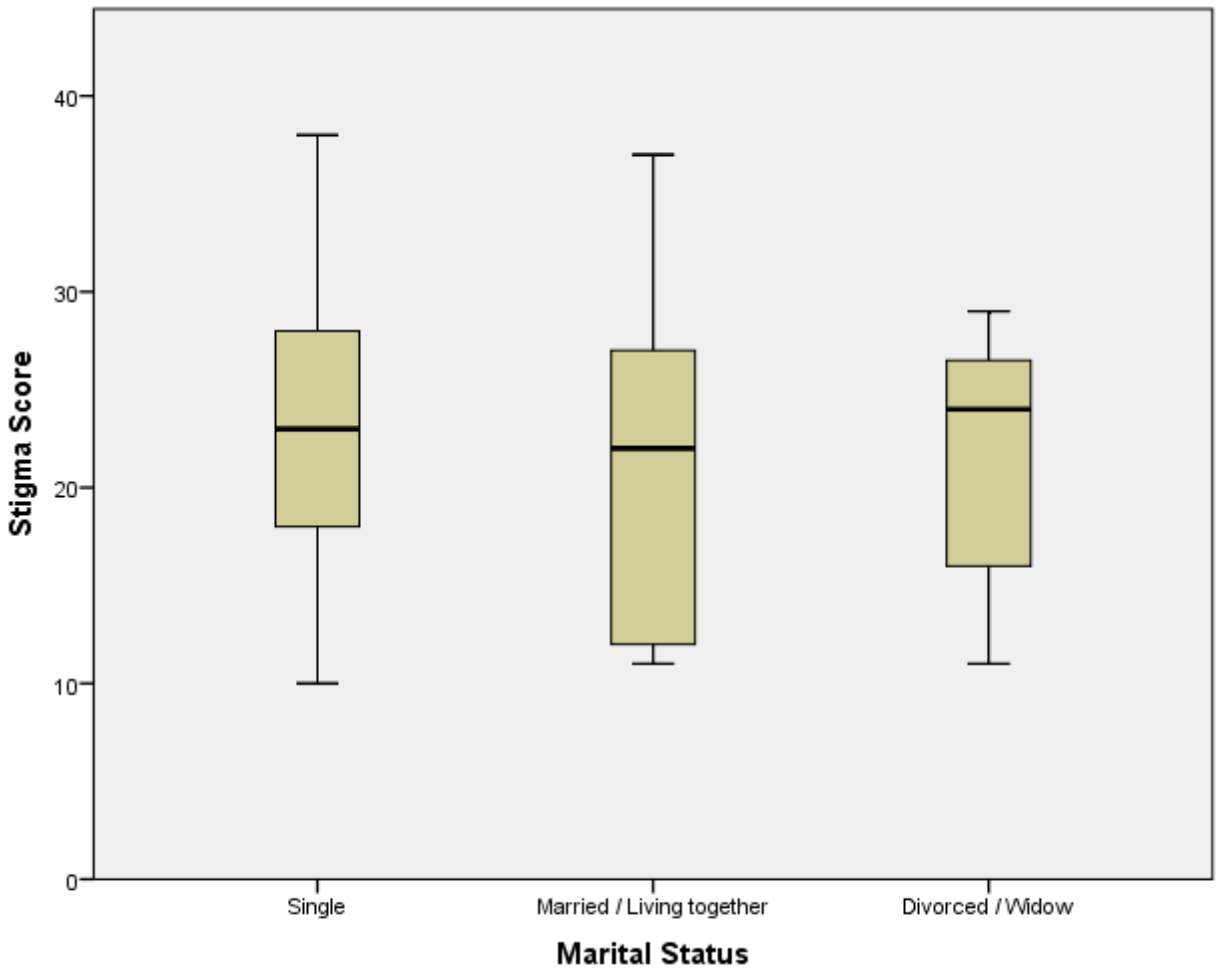

Figure 13- Box plot - Stigma score and marital status

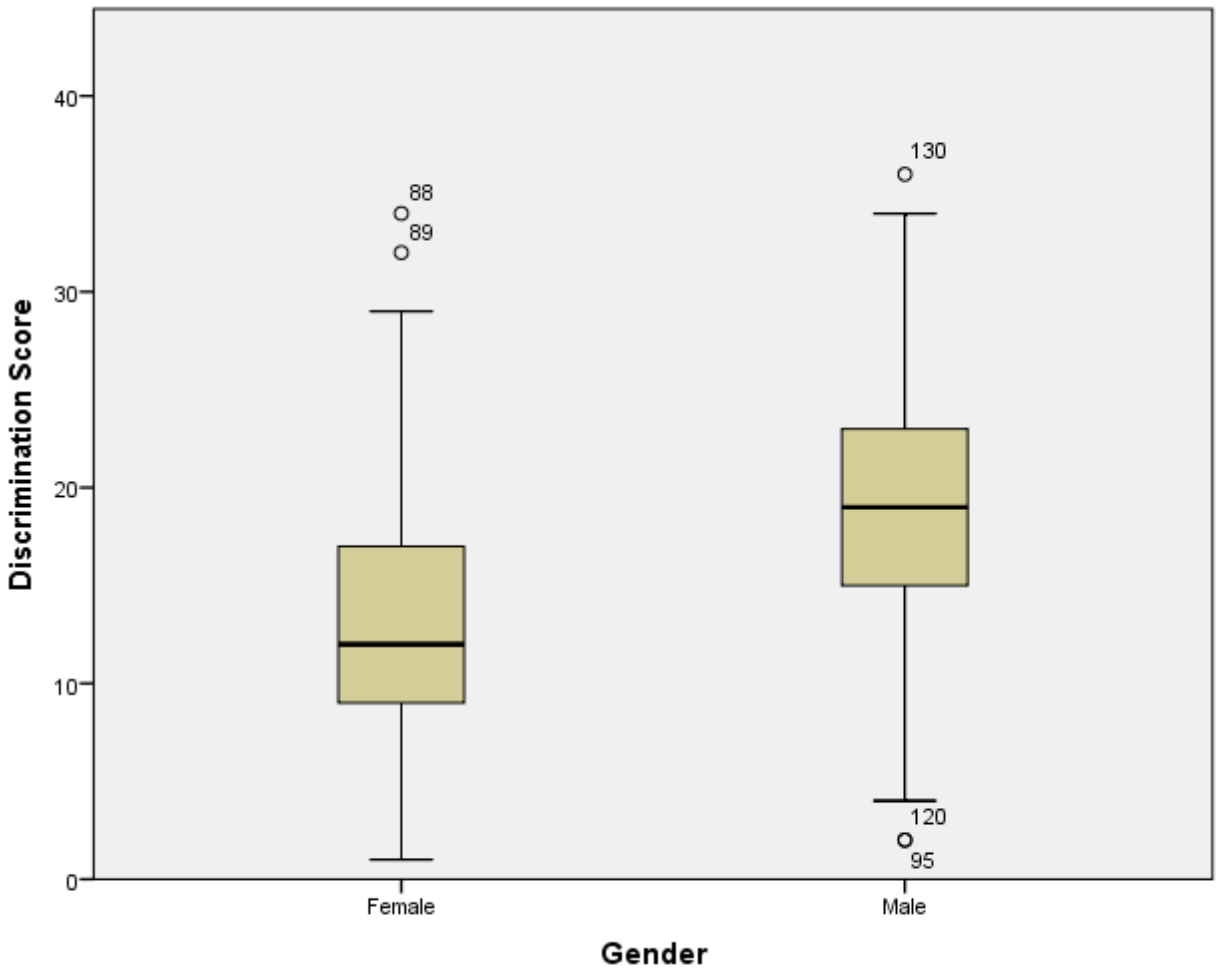

Figure 14- Box plot - Discrimination score and gender

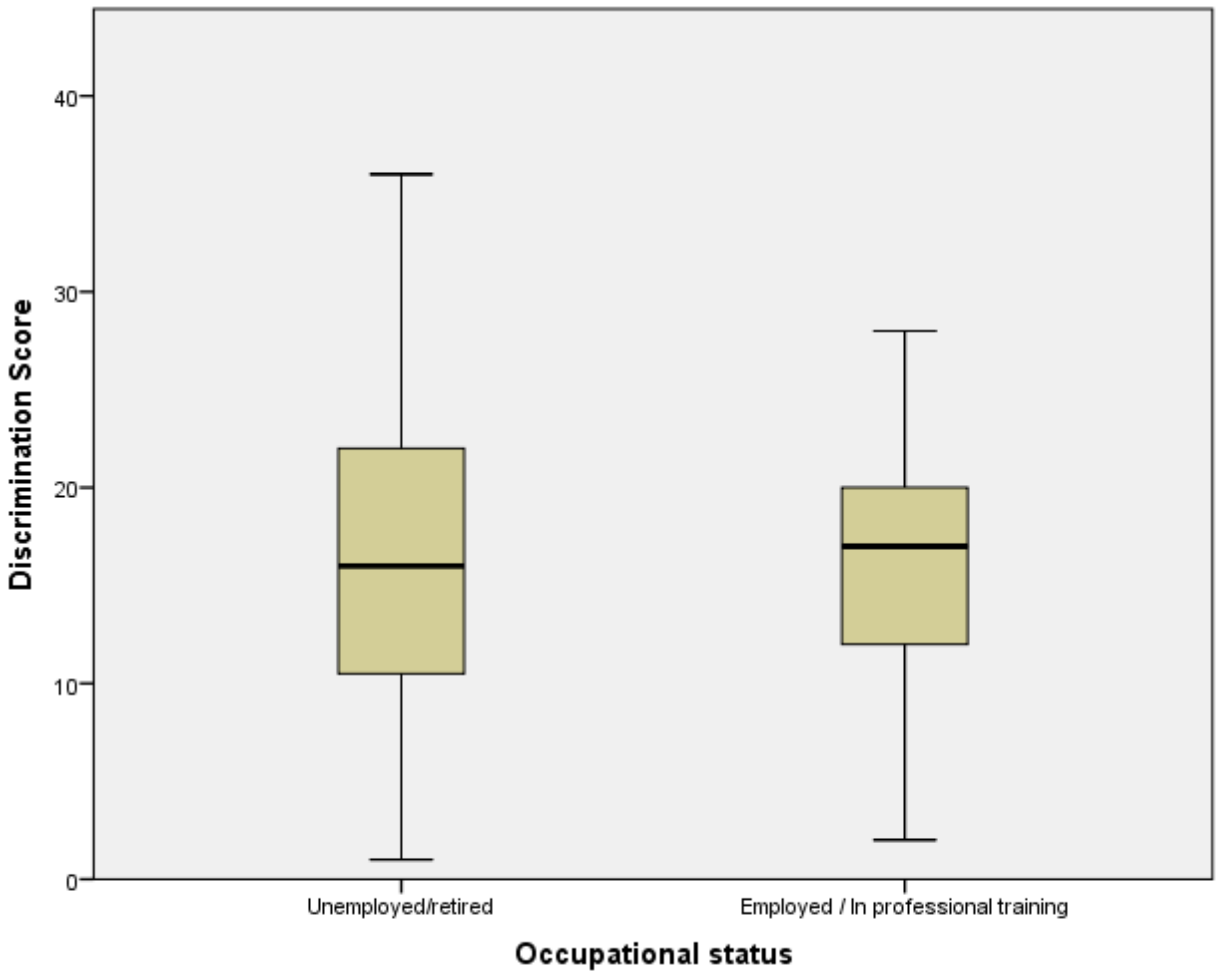

Figure 15- Box plot - Discrimination score and employment status

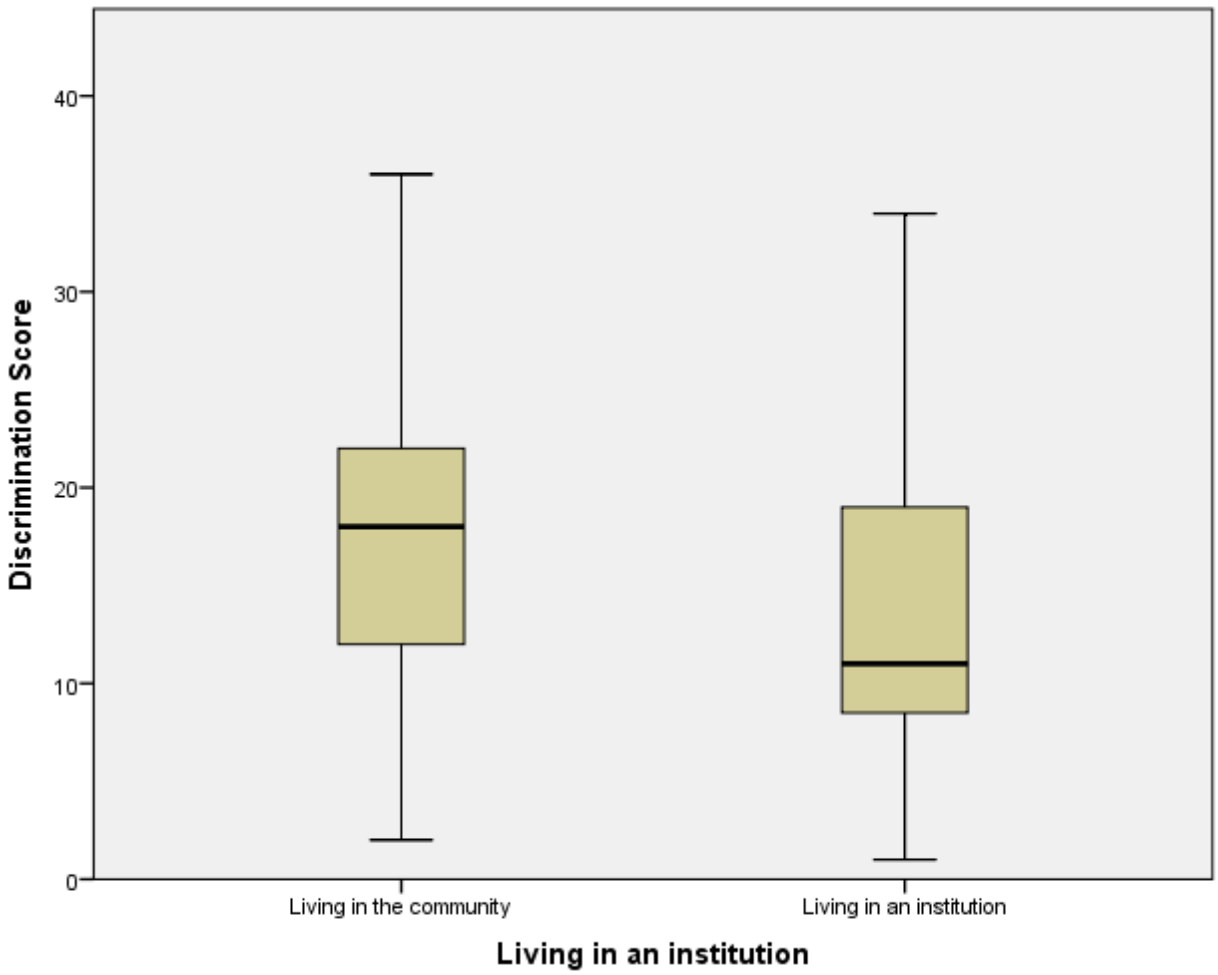

Figure 16- Box plot - Discrimination score and institutionalization

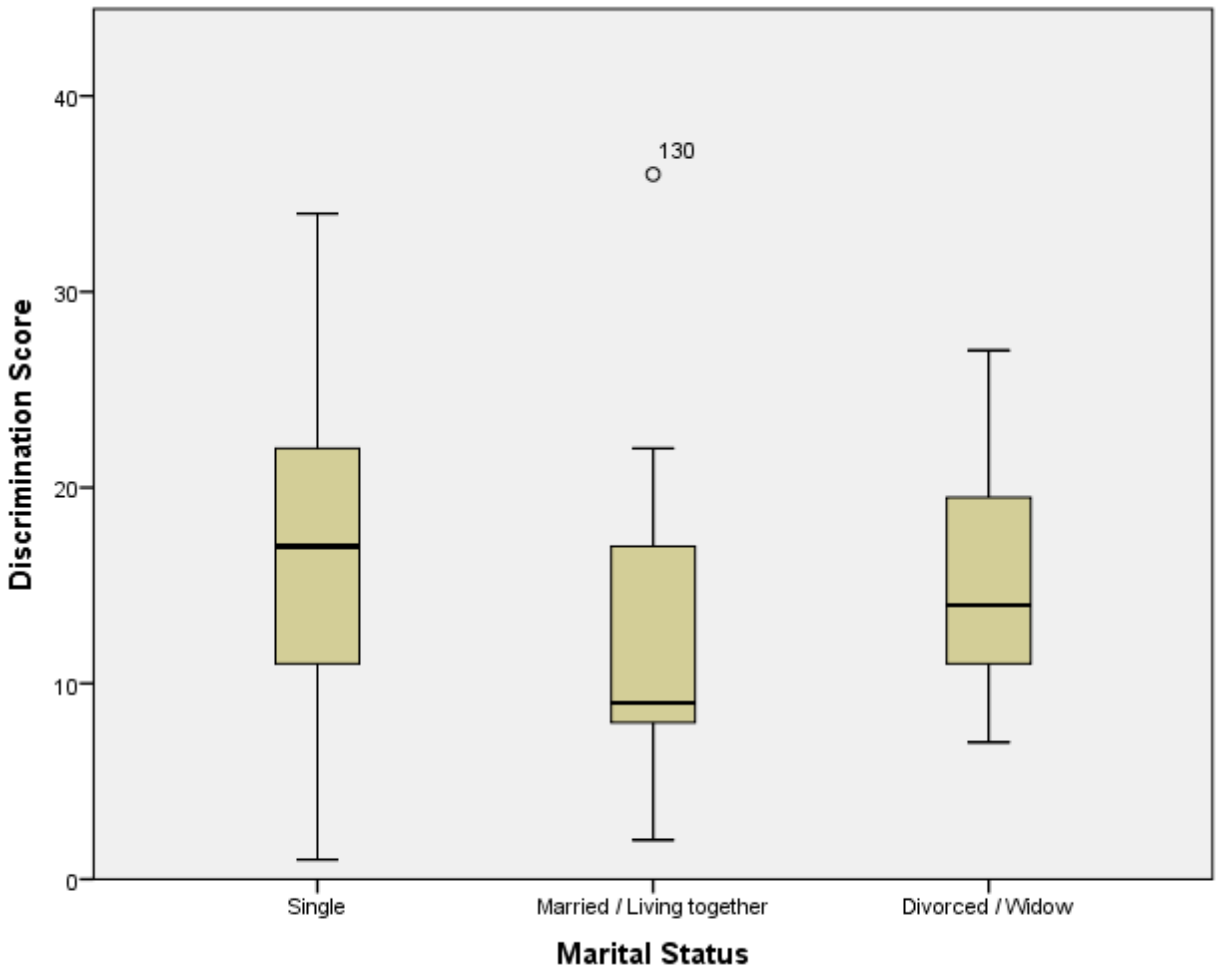

Figure 17 - Box plot - Discrimination score and marital status

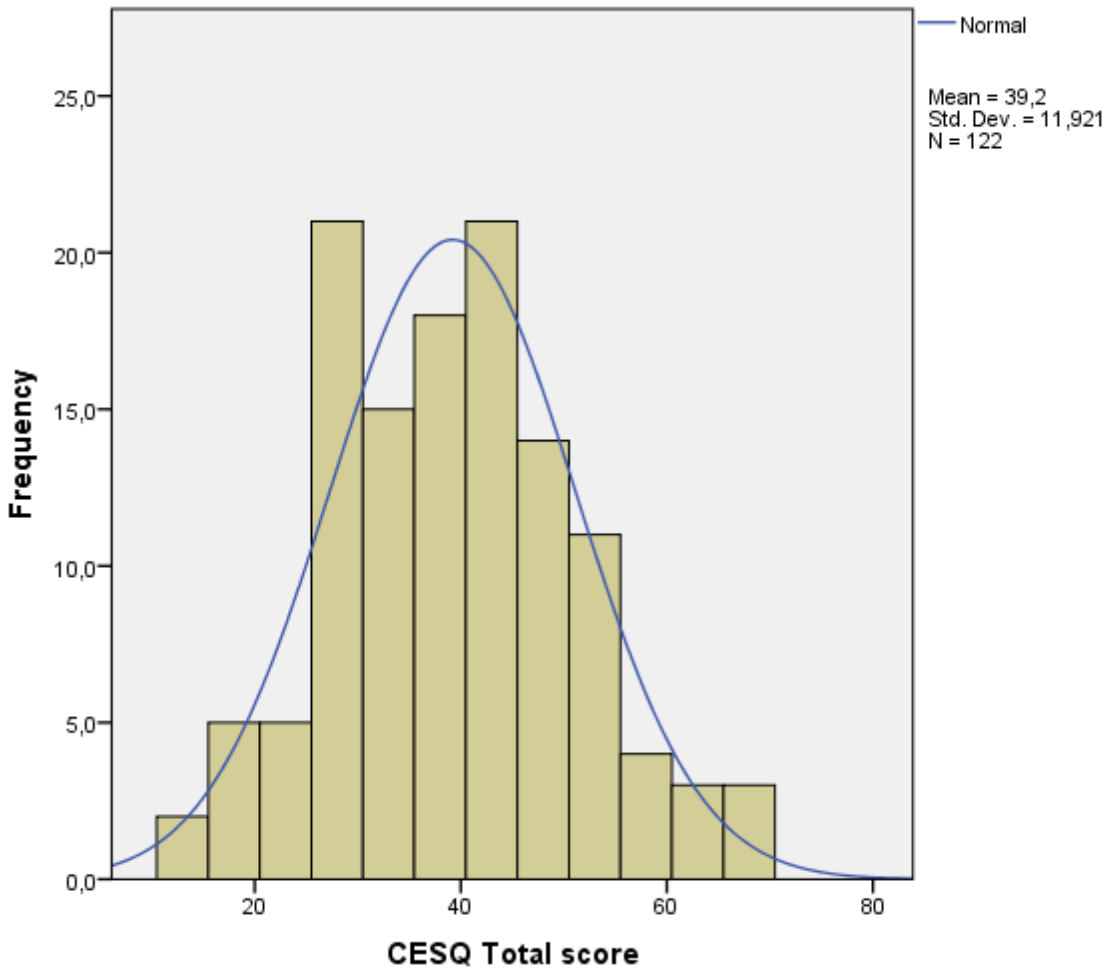

Figure 18 - Histogram for CESQ Total Score

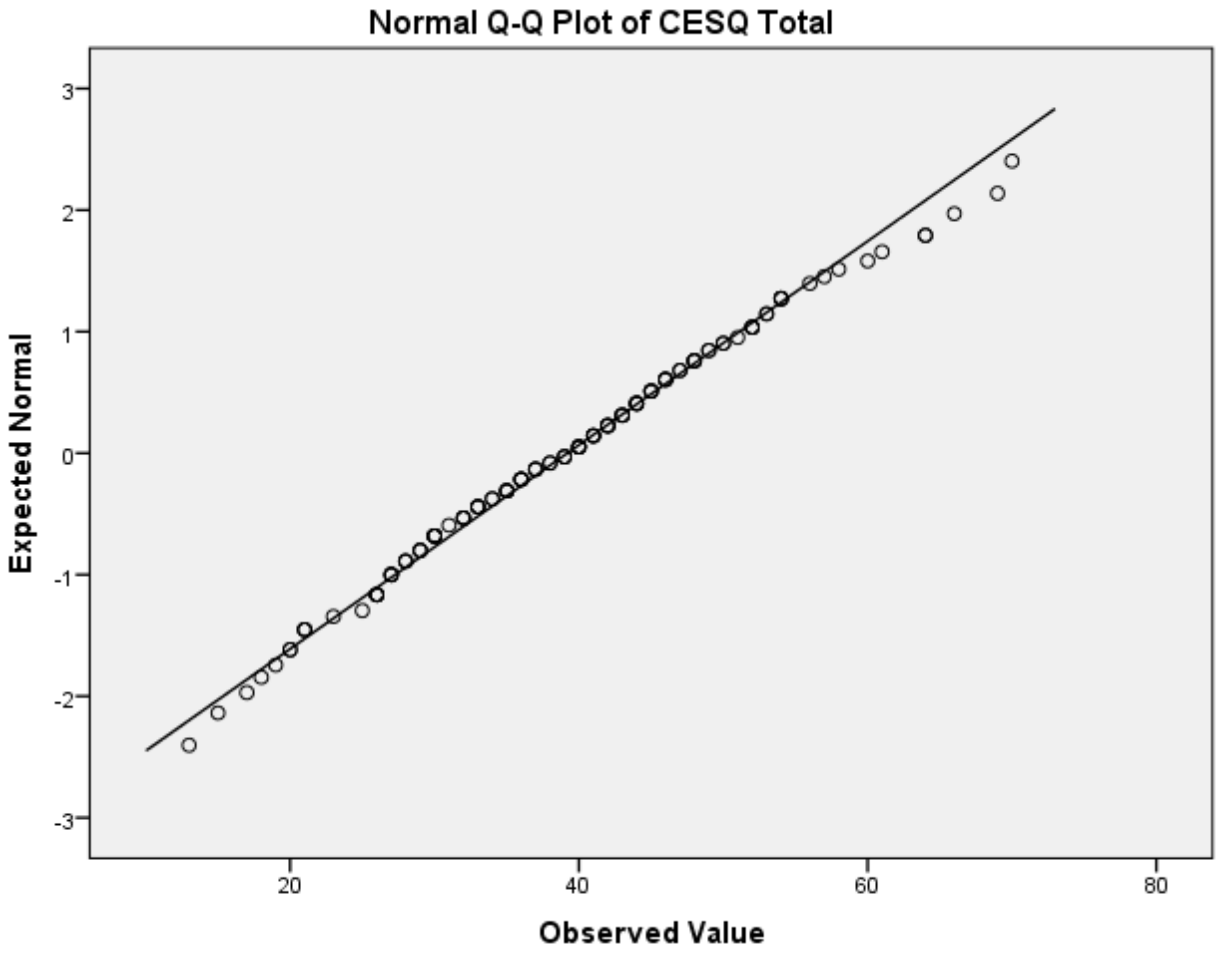

Figure 19 - Normal QQ Plot of the CESQ total score

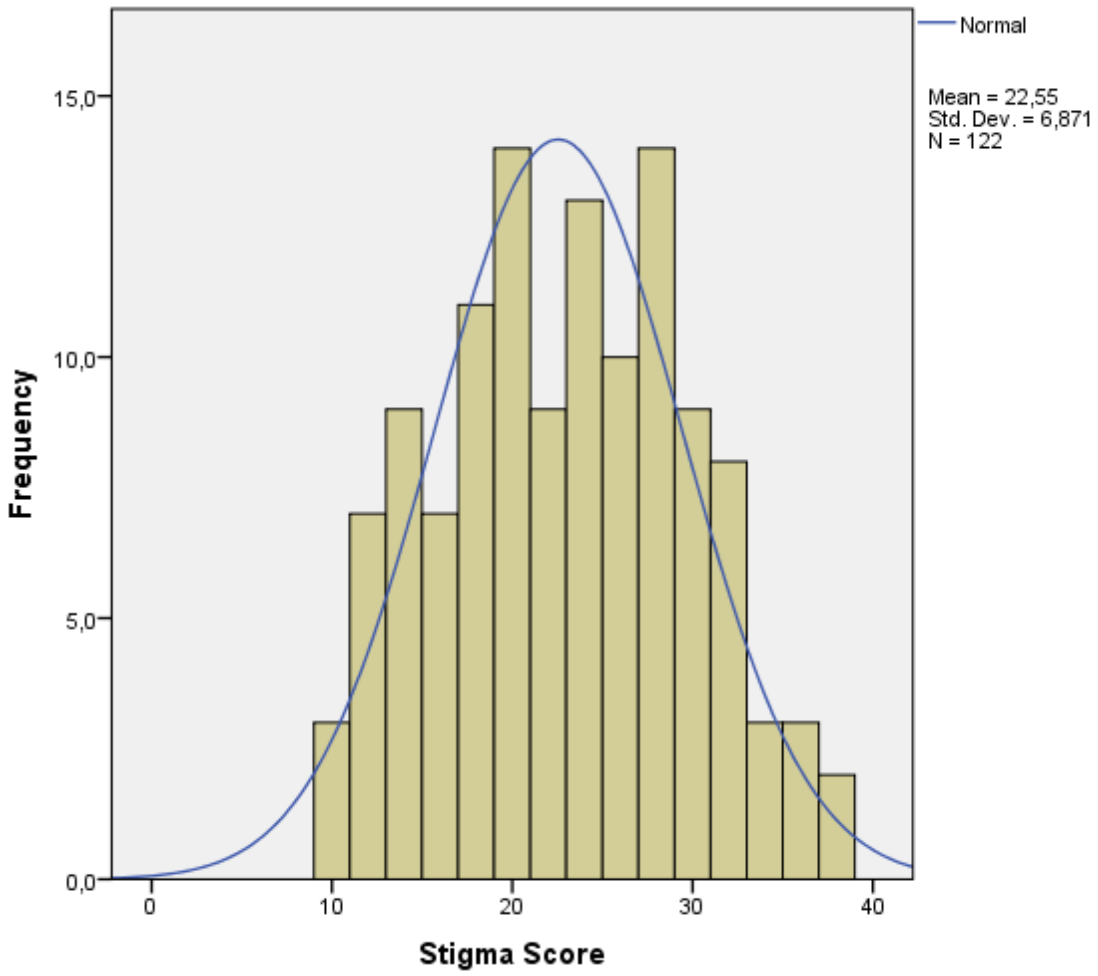

Figure 20 - Histogram for score of the stigma subscale

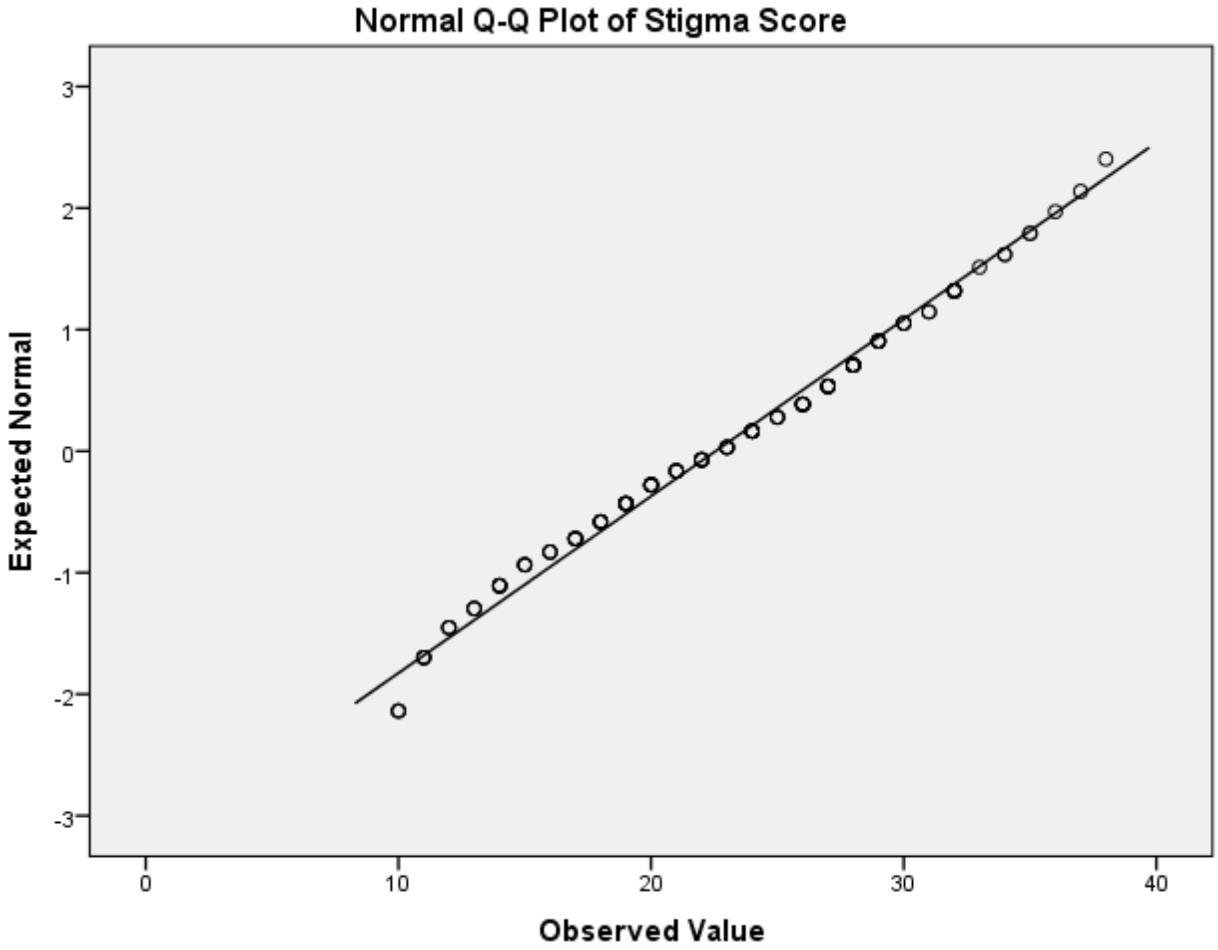

Figure 21 - Normal QQ Plot of the stigma subscale

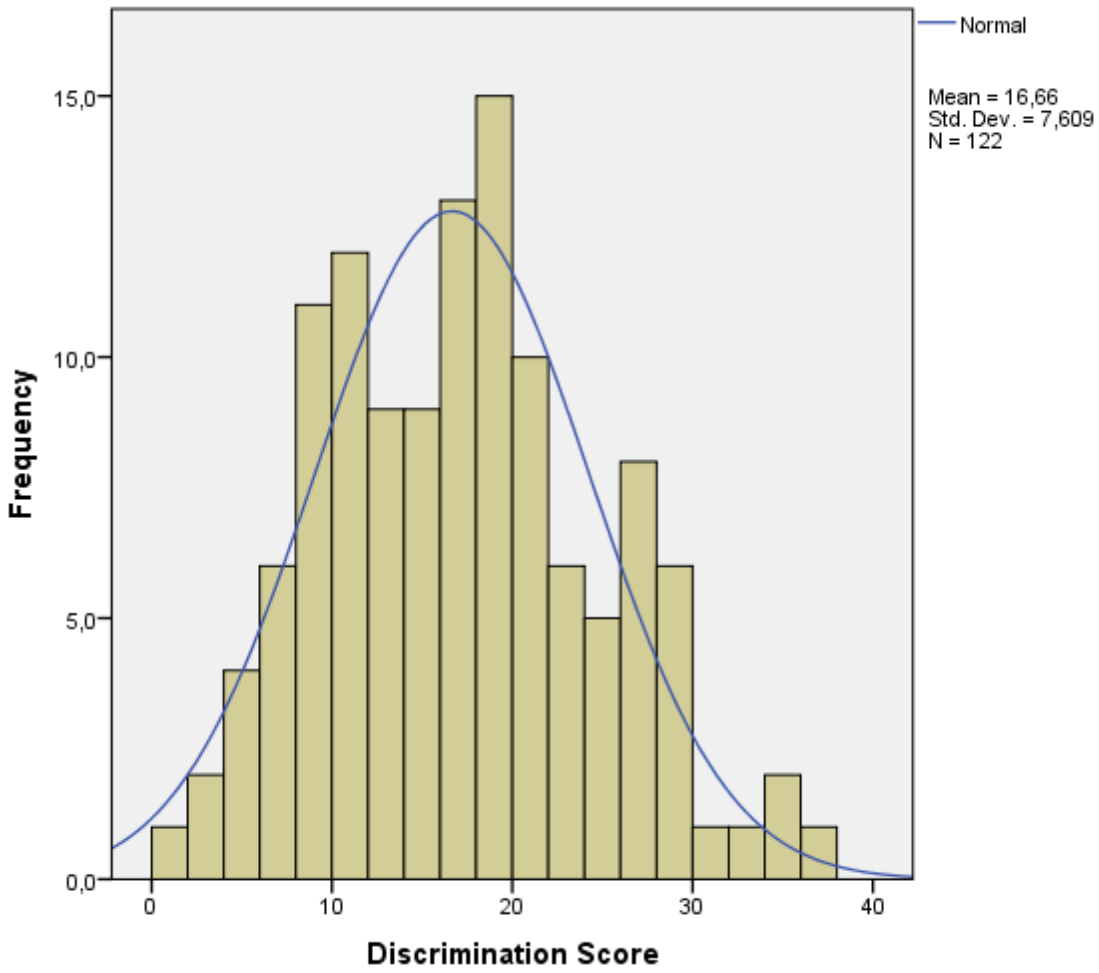

Figure 22 - Histogram for score of the discrimination subscale

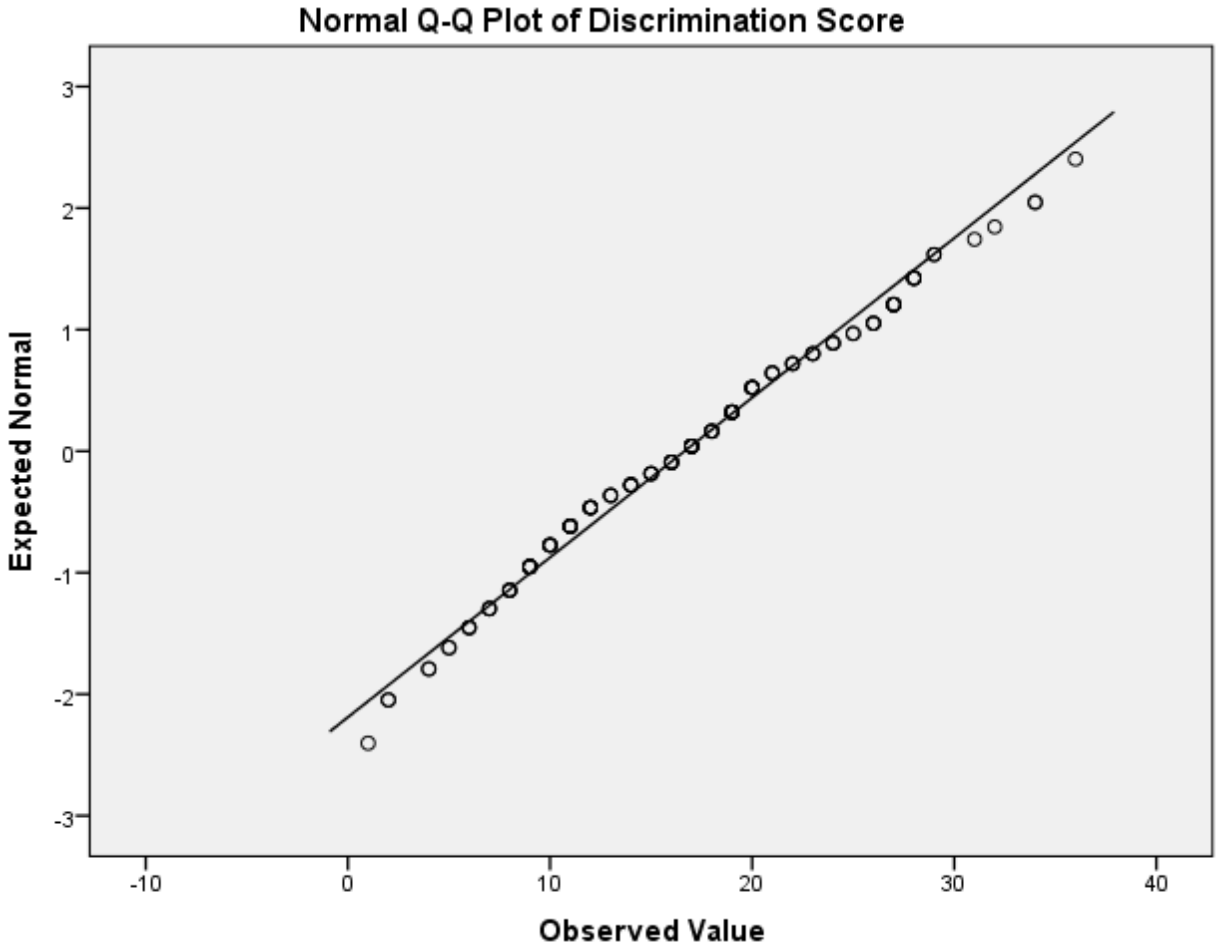

Figure 23 - Normal QQ Plot of the discrimination subscale

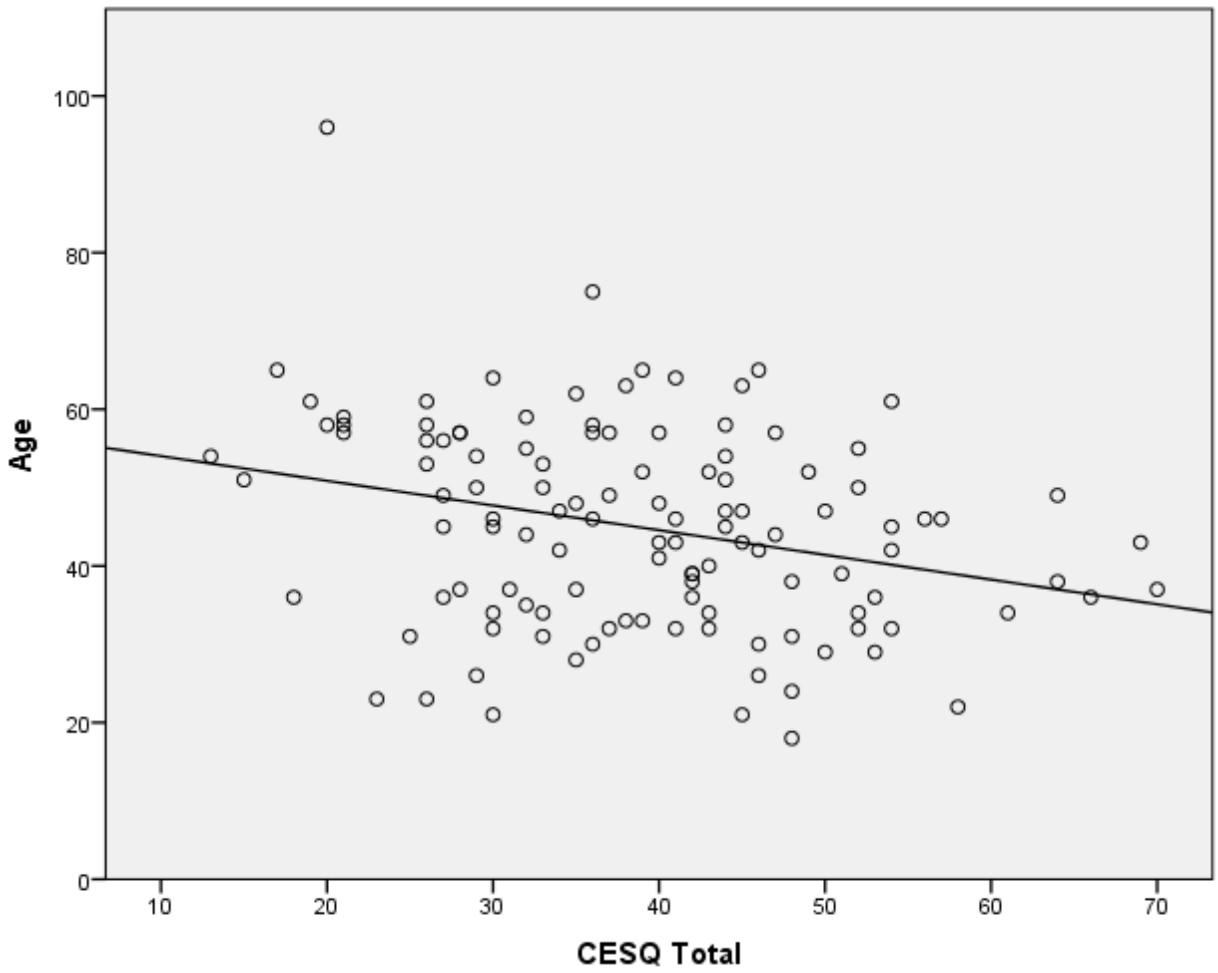

Figure 24 - Scatter Plot - Total CESQ Score and age

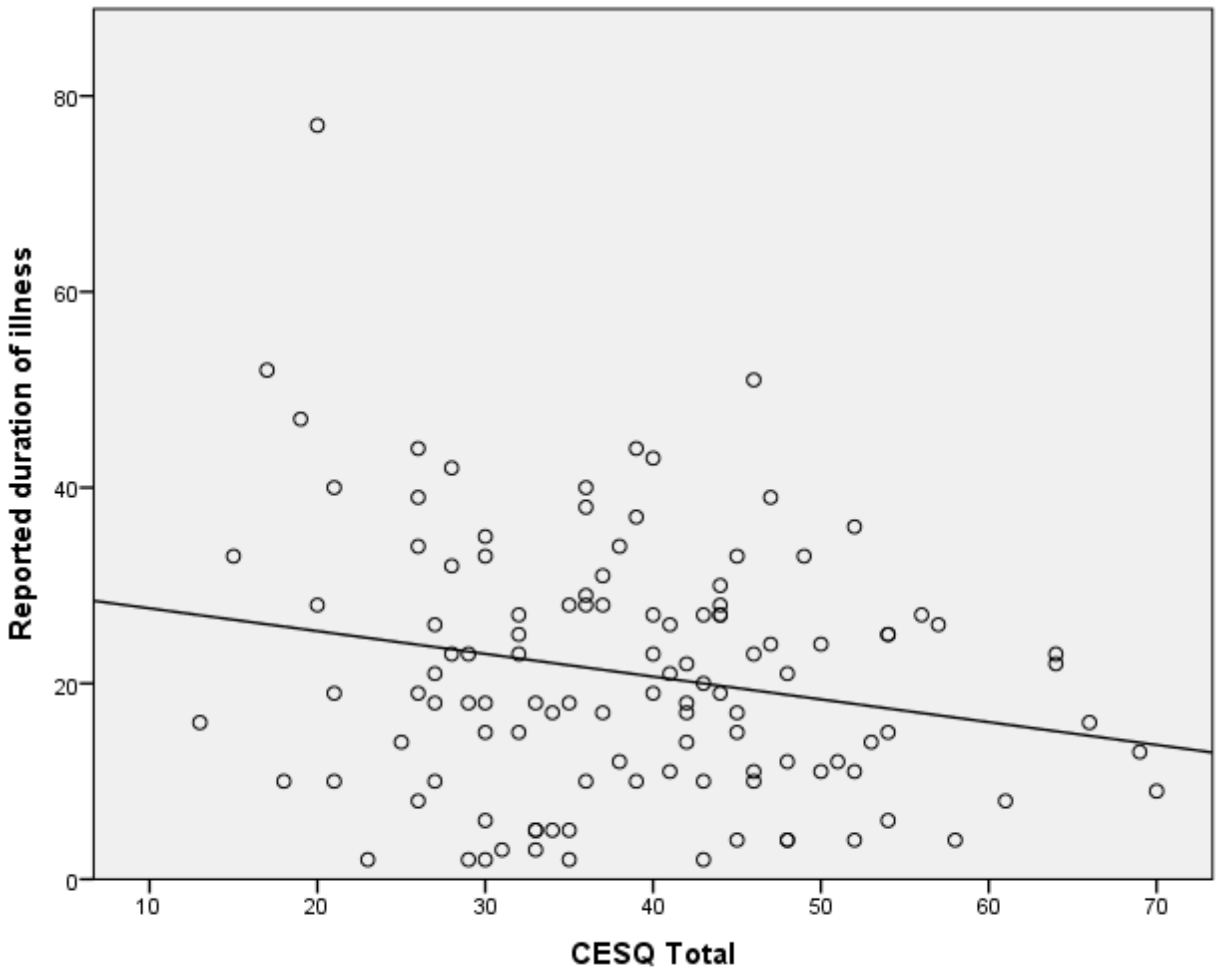

Figure 25 - Scatter Plot - Total CESQ Score and reported duration of illness

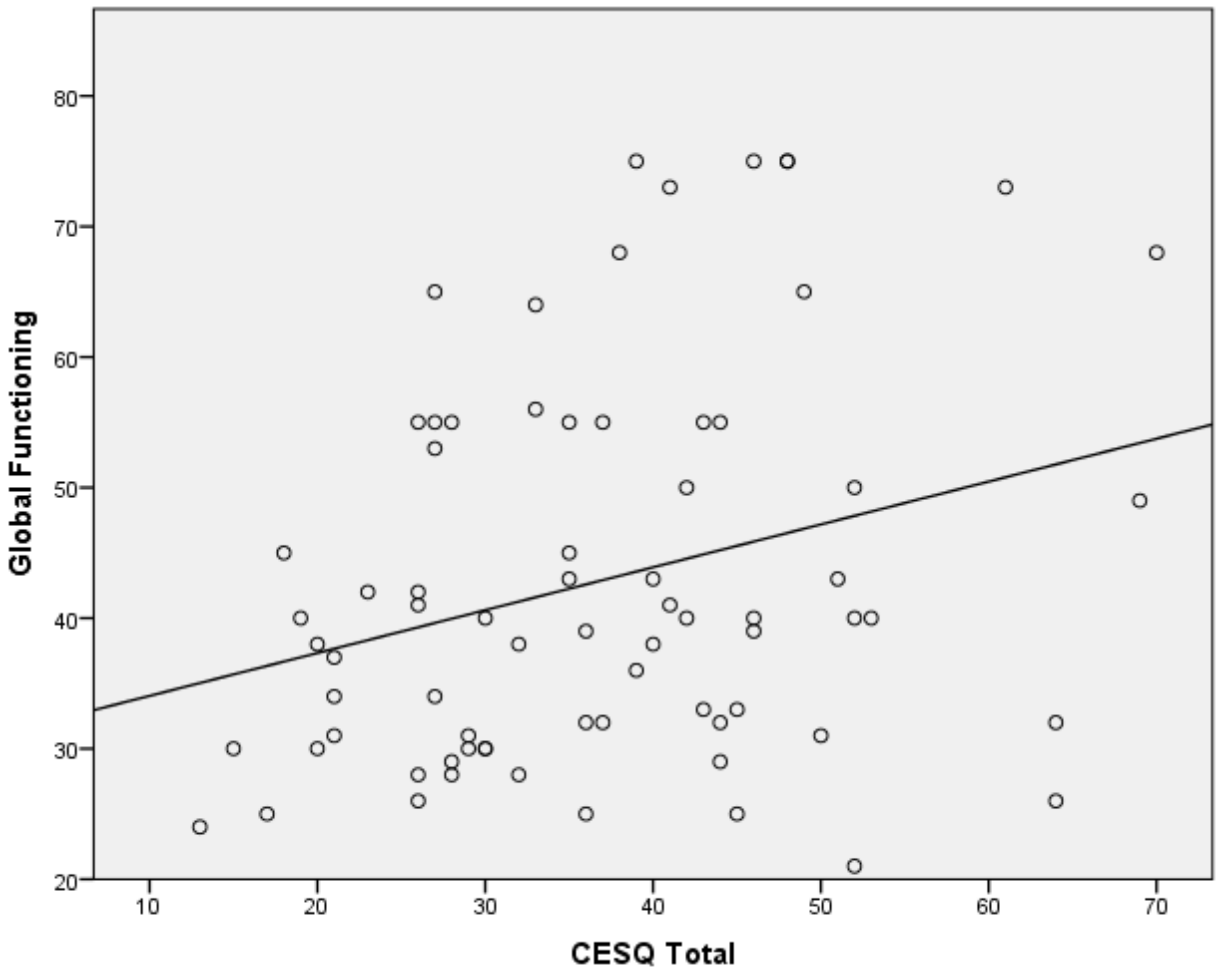

Figure 26 - Scatter Plot - Total CESQ Score and global functioning

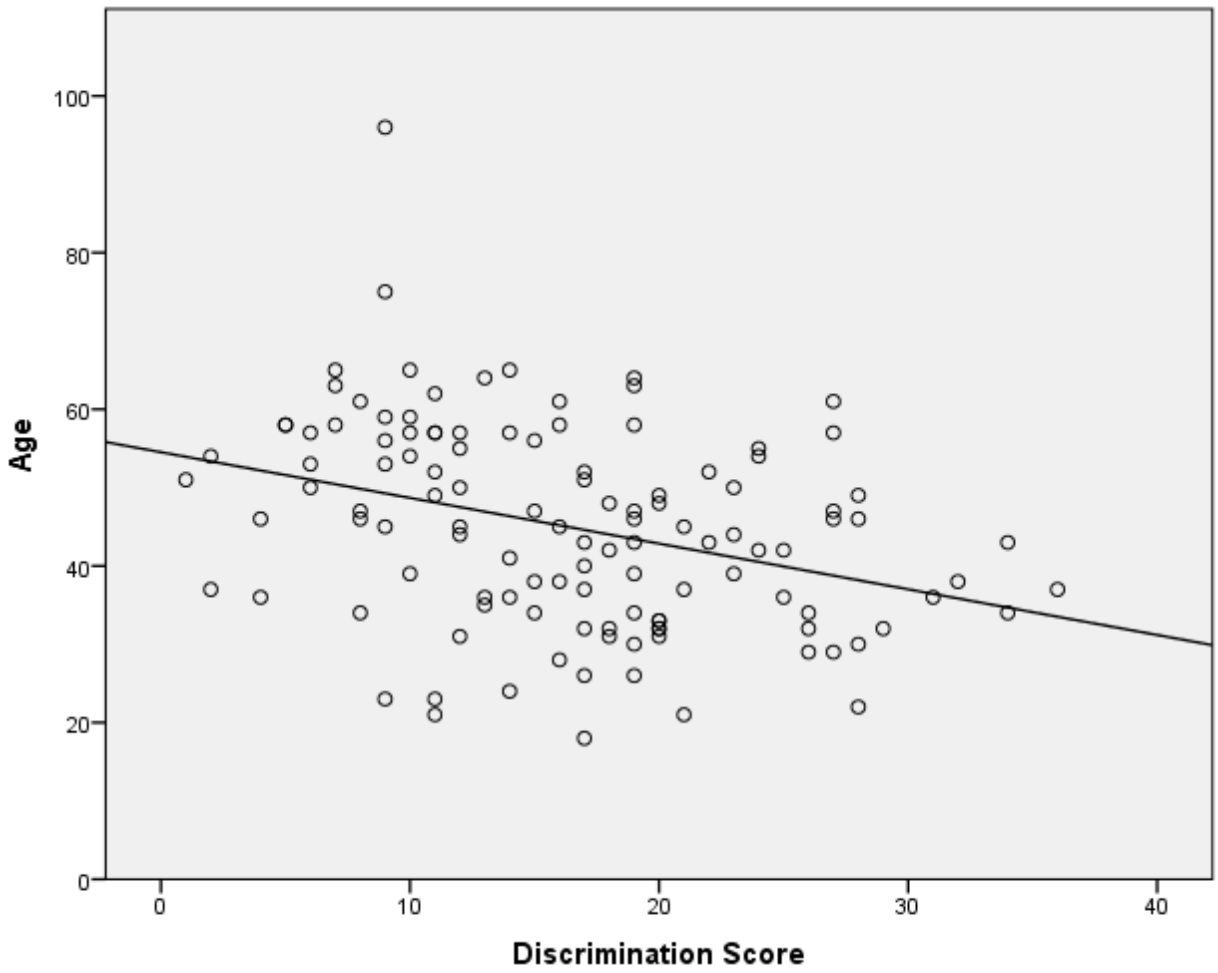

Figure 27 - Scatter Plot - Discrimination score and age

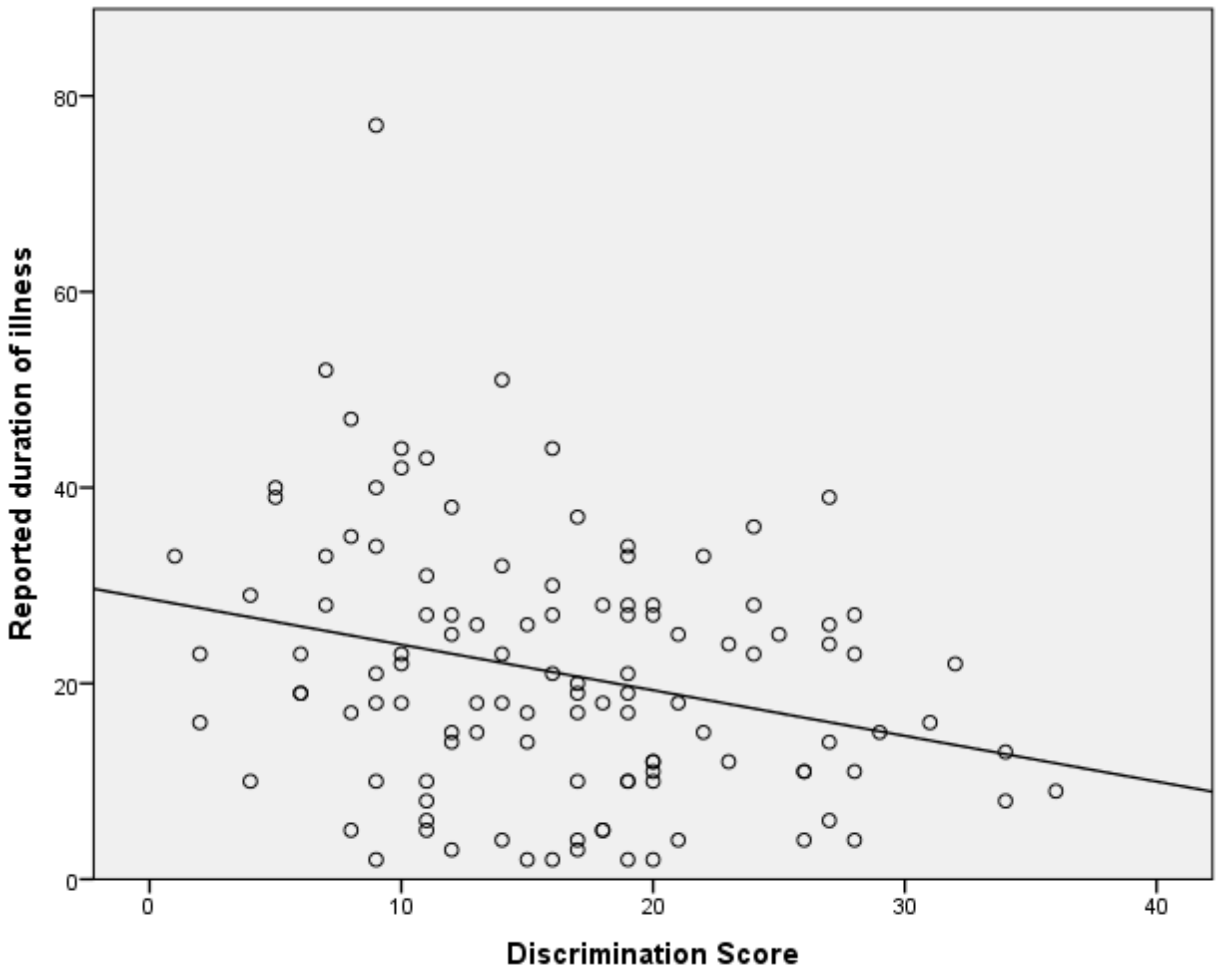

Figure 28 - Scatter Plot - Discrimination score and reported duration of illness

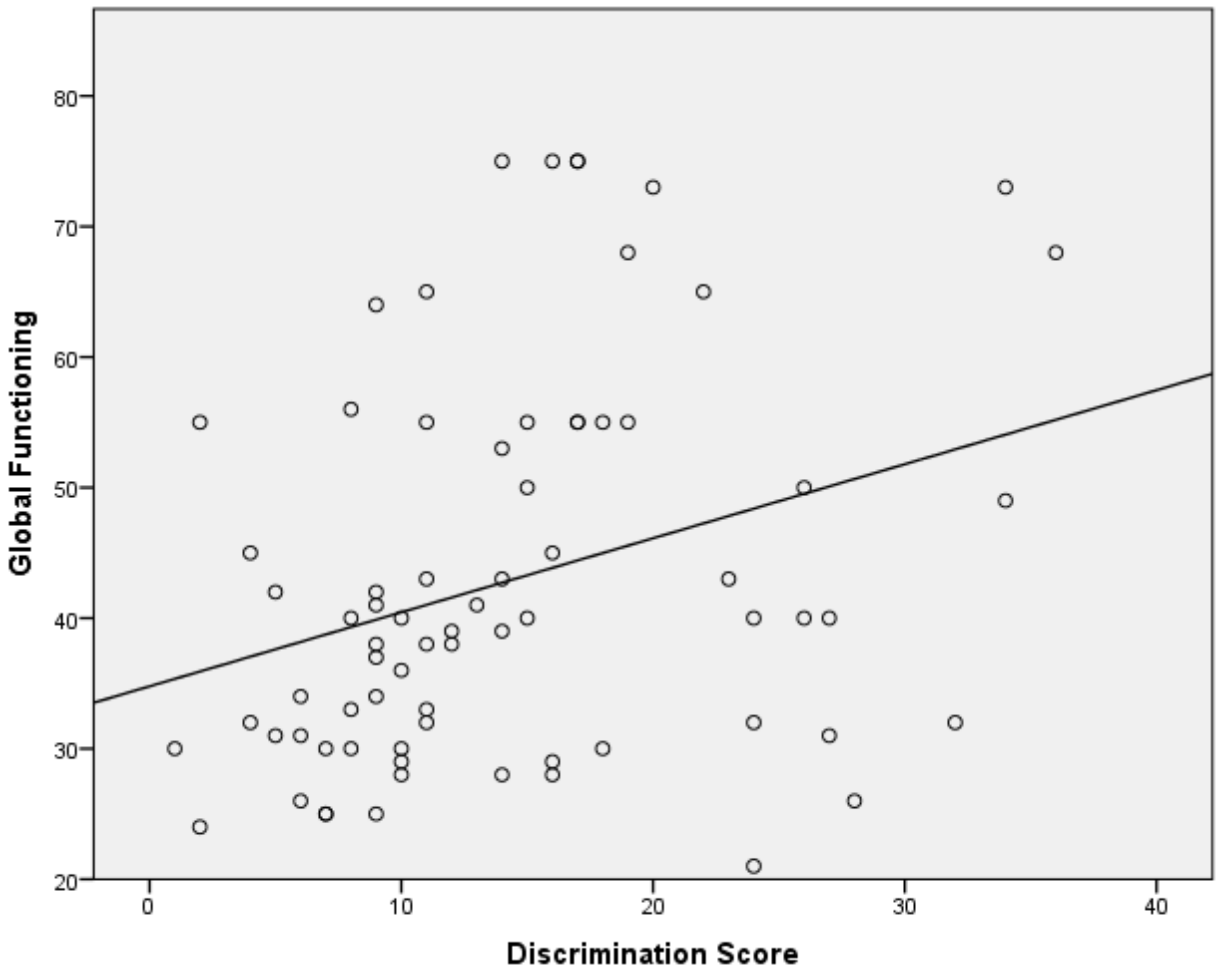

Figure 29 - Scatter Plot - Discrimination score and global functioning

5 OTHER TABLES

Table 9 - Detailed demographic characteristics of the sample

		ARIA	Idanha	FAPS
n		49	42	31
Gender	Female (%)	13 (26,5%)	36 (85,7%)	5 (16,1%)
	Male (%)	36 (73,5%)	6 (14,3%)	26 (83,9%)
Age	Mean:	39,54	54,88	39,32
	SD:	10,572	10,816	11,047
	Range	18-64	34-96	23-63
Marital status	Single (%)	43 (87,8%)	30 (71,4%)	25 (80,6%)
	Married / Living together (%)	1 (2,0%)	4 (9,5%)	4 (12,9%)
	Divorced / Widow (%)	5 (10,2%)	8 (19,0%)	2 (6,5%)
Living status	Living alone	11 (22,9%)	3 (7,0%)	4(12.9%)
	Living with family support	31 (64,6%)	5 (11,9%)	28 (87.1%)
	Homeless	1 (1,7%	0 (0%)	0 (0%)
	Living in an institution	5 (8,3%)	34 (81,0%)	0 (0%)
Occupational status	Unemployed / Retired	35 (74.5%)	36 (85.7%)	28 (90.3%)
	Employed / In professional training	12 (25.5%)	6 (14.3%)	3 (9.7%)

Table 10 – Detailed clinical characteristics of the three subsamples

		ARIA		Idanha		FAPS	
		n	%	n	%	n	%
Diagnosis	Schizophrenia (F20.0)	9	64,3	23	54,8	27	87,1
	Bipolar disorder (F31)	2	14,3	10	23,8	0	0
	Schizoaffective disorder (F25)	2	14,3	4	9,5	2	6,5
	Depression (F32.3)	1	7,1	5	11,9	0	0
	Delusional disorder (F22)	0	0	0	0	2	6,5
	n for diagnosis	14	100	42	100	31	100
Reported age at onset of illness (years)	Mean	23,59		26,17		21.42	
	SD	8.162		9.594		6.682	
	Range	14-55		13-57		11-39	
	n for reported age of onset of illness	44		42		31	
Reported duration of illness (years)	Mean:	15,7		28,71		17,90	
	SD:	9,471		13,883		11,703	
	Range	2-39		5-77		2-47	
	N for reported duration of illness	43		42		31	
Global Functioning (GAF Score)	Mean	Not reported		34.8		53.8	
	SD			9.02		14.20	
	Range			21-64		30-75	
	N for Global function (GAF score)			42		31	